DOCUMENT RESUME

ED 295 729 PS 017 376

TITLE Federal Employee Family-Building Act of 1987. Hearing on H.R. 2852 before the Subcommittee on Civil Service of the Committee on Post Office and Civil Service. House of Representatives, One Hundredth Congress, First Session.

INSTITUTION Congress of the U. S., Washington, D. C. House Committee on Post Office and Civil Service.

PUB DATE 23 Jul 87

NOTE 81p.; Serial No. 100-22.

AVAILABLE FROM Superintendent of Documents, Congressional Sales Office, U.S. Government Printing Office, Washington, DC 20402 (Stock No. 552-070-026-80-1, $2.50).

PUB TYPE Legal/Legislative/Regulatory Materials (090)

EDRS PRICE MF01/PC04 Plus Postage.

DESCRIPTORS Adjustment (to Environment); *Adoption; Costs; *Family (Sociological Unit); Family Problems; *Federal Government; *Federal Legislation; *Fringe Benefits; *Government Employees; Hearings; Medical Services

IDENTIFIERS Fertility; *Fertilization; Proposed Legislation

ABSTRACT

A hearing was held to consider H.R. 2852, the Federal Employee Family-Building Act, a proposal that would require health insurance plans for federal employees to cover the costs of adoption and fertility treatments. Testimony concerned: (1) difficulties childless and infertile federal employees encountered in efforts to adopt and conceive children; (2) basic statistics on infertility and basic information on the medical treatment of infertility; (3) in vitro fertilization and other treatments; (4) the nature of treatment; (5) costs of adoption; (6) costs of infertility; and (7) stages in the emotional process of adjusting to infertility. Additional materials submitted for the record include an article on professional and commercial aspects of in vitro fertilization, and fact sheets on adoption, infertility, and the Federal Employee Family-Building Act. (RH)

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FEDERAL EMPLOYEE FAMILY-BUILDING ACT OF 1987

HEARING

BEFORE THE

SUBCOMMITTEE ON CIVIL SERVICE

OF THE

COMMITTEE ON POST OFFICE AND CIVIL SERVICE HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

FIRST SESSION

ON

H.R. 2852

A BILL TO AMEND TITLE 5, UNITED STATES CODE, TO PROVIDE THAT ANY CARRIER OFFERING OBSTETRICAL BENEFITS UNDER THE HEALTH BENEFITS PROGRAM FOR FEDERAL EMPLOYEES SHALL ALSO PROVIDE BENEFITS RELATING TO CERTAIN "FAMILY-BUILDING PROCEDURES", AND FOR OTHER PURPOSES

JULY 23, 1987

Serial No. 100-22

Printed for the use of the Committee on Post Office and Civil Service

PS 017376

U.S. GOVERNMENT PRINTING OFFICE
76-946 WASHINGTON : 1987

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FEDERAL EMPLOYEE FAMILY-BUILDING ACT OF 1987

THURSDAY, JULY 23, 1987

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON CIVIL SERVICE,
COMMITTEE ON POST OFFICE AND CIVIL SERVICE,
Washington, DC.

The subcommittee met, pursuant to call, at 10 a.m., in room 311, Cannon House Office Building, Hon. Patricia Schroeder, chairwoman, presiding.

Mrs. SCHROEDER. Welcome to today's hearing on H.R. 2852, the Federal Employee Family-Building Act. This proposal would require health insurance plans for federal employees to cover the costs of adoption and fertility treatments.

Infertility can be a horrible problem. You seldom die from it, but the pain is profound. When you want children, the inability to have them comes as a terrible surprise. It undermines marriages, careers and self-image. And the problem is widespread: nearly 5 million couples, maybe as many as one out of every five, have trouble conceiving.

In the last few years, medical science has made tremendous strides in the treatment of infertility. Microsurgical techniques and drug therapy have given hope to thousands of couples. But, for many, these advancements mean little since the cost precludes them from seeking treatment.

Insurance companies have been slow to cover treatment for infertility. They say it's too expensive; they say it's needed by too small a population; they say it's experimental; they say it's not health related. Their logic is screwy. Federal health plans even cover the costs to become infertile through vasectomies and tubal ligations, but not the costs to overcome infertility.

The costs of infertility treatments average around $3,000; the fees for adoption around $6,000. Although these costs, just as most health care costs, can be prohibitive when shouldered by individuals, they add little to the Nation's health care bill when covered by insurance and spead over the entire employee population.

Although couples of lesser means have a higher incidence of infertility, it is only the well-to-do who can pursue treatment. This bill will correct this inequity by bringing family building within the reach of all working couples.

As you can see, we already have a vote, so I will take a temporary recess and be right back and, hopefully, we can proceed with the first panel.

[A short recess was taken.]

Mrs. SCHROEDER. Thank you.

I am going to reconvene the hearing. Let me call up the first panel. First, we have Kim Gore, from the Department of Defense, speaking for herself. She is accompanied by Jimmy Peters, Holly and Bryan from Occoquan, VA.

And then we have Mr. Lawrence Miller, accompanied by Benjamin, and chief administrative law judge, Robert E. Sears from the Department of Health and Human Services, speaking for himself, accompanied by Ms. Leeanne Sears and Ashland Victoria, from Norfolk, VA.

If you would all like to come up to the front, we welcome you and are delighted you are here.

I must say there are some of the cutest children here. We are really glad to have the children, because that is what this is all about. This is not about something special for adults, it is something special for children. We welcome them, and whoever wants to lead off. Kim, would you like to lead off?

Ms. GORE. Sure.

Mrs. SCHROEDER. Terrific, Kim, you are up.

STATEMENT OF KIM GORE, DEPARTMENT OF DEFENSE, ACCOMPANIED BY JIMMY PETERS, HOLLY AND BRYAN

Ms. GORE. My name is Kim Gore, and I am a DOD employee. I have worked for the Government for almost 14 years now. And in December of 1985, we adopted Holly. And Holly is an in-State adoption, in the State of Virginia, and we got her within 2 months after applying. And when we started going to adoption agencies, we were really flabbergasted at the expenses, and we were told we would probably have a child in our home within 14 months, or so.

And then they called us a couple of weeks later and told us to pick up our daughter. So, we had to come up with $7,000 in less than a week. And we had to go to the credit union and take out a loan, and clean out our savings. And we came up with it, and we paid the money and picked up our daughter.

And then 8 months after Holly was in our home, I got pregnant with Bryan. So, now we have two kids and there is 17 months between them. But with Bryan the medical expenses ran to about $7,000, but the insurance company paid all but $300. With Holly, it cost $7,000 and we got no financial assistance, except through Jimmy's company, who had an adoption assistance plan. And they reimbursed us $1,000; so it came to $6,000 that we had to cough up ourselves.

And before I got pregnant with Bryan, we just assumed Holly would be an only child, because we didn't think we could afford to do that again.

So, we really support this bill, because it seems like adoption is only going to be available to the rich. And you know, you don't have to be rich to be a good parent.

Mrs. SCHROEDER. Absolutely. You make a very, very good case.

[The prepared statement follows:]

15 July 1987

Subcommittee on Civil Service
Committee on Post Office and Civil Service
United States House of Representatives

Dear Subcommittee Members:

On December 13, 1986 (Friday the 13th) my husband and I were blessed by the coming home of our daughter Holly Germaine Peters. Holly came to us through adoption. She was a beautiful, alert, healthy eight week old baby. Although she had no physical or mental handicaps, she was considered Special Needs/Hard to Place because of her racial ancestry. Holly is a unique mixture of white, black and Indian.

Five months prior to becoming Holly's parents, I lost a child through miscarriage in the third month of pregnancy. My husband and I had been together 13 years and this was my first pregnancy despite the fact I had never done anything to prevent it. After losing this child, my husband and I seriously discussed adoption. We made inquiries to many adoption agencies to acquire information. We were in no way prepared for the hard facts concerning adoption including the extremely high costs to be bore by the potential adoptive parents.

After discussing the situation, we contacted an organization called Families Adopting Children Everywhere (F.A.C.E.), a support group for adoptive and potential adoptive parents. We were told by F.A.C.E. members that the rates given to us were basically the average standard rates (approximately $6,000 for domestic, and no less than $10,000 international). We decided to try adopting through the Pan American Adoption Agency in Manassas, Virginia.

After registering with Pan American and signing a contract as a potential adoptive family in October 1985, a Pan American staff member was assigned to complete a home study on us. The home study process consisted of three visits to our home by the Pan American staff member. Prior to the visits, my husband and I completed and forwarded autobiographies to the agency. After all visits are completed, the staff member wrote a report based on her findings through interviews and our autobiographies. In this report she made recommendations regarding our capabilities as potential parents. During the last visit we were told we would probably have a child in our home by December 1988, 13 months away. This was a satisfactory arrangement because it would give us time to accumulate some of the placement fees.

The week after Thanksgiving 1985 the Director of the Pan American Adoption Agency informed us that there were two multi-racial infants available through the Catholic Family Services in

Roanoke, Virginia and asked if we would be interested. We had already expressed interest in bi-racial and multi-racial children during the home study. We of course said "yes"! The next Sunday night she again called us to tell us we were seriously being considered for one of these children, a girl. The very next night she called again and said, "You will be expected in Roanoke at 10:00 AM next Friday to pick-up your little girl!

We were elated but we had little time to prepare for starting our family. We scurried around trying to beg, borrow, or buy necessary baby items. We were also pressed with coming up with more than $6,000 in less than a week. My husband went to our credit union, the AMC Federal Credit Union, and pleaded for financial aid. A Credit Union loan officer and my husband discussed the situation and came up with a solution that we could probably handle financially. We practically deleted all savings and acquired a loan to finance our family building. On Friday, December 13, 1985, two days after delivering the money, we brought our child home. A year and a half later we were blessed again with the birth of our biological son, Bryan Jennings Peters, on March 27, 1987.

We feel very fortunate to have two healthy children. They are a blessing no matter how they come to you. We also feel fortunate to have experienced family building through both adoption and birth. Although the end result is the same, there are many differences between these two methods of family building.

My Federal Government Health Insurance Program, Choice, will cover all but approximately $300 of medical expenses incurred during my pregnancy. It was a difficult pregnancy during which many tests were performed. Bryan was in the breech position so he was delivered by a Cesarean Section. Therefore, the total medical costs were over $7,000.

When I left the hospital with Bryan I was given a Gift Pack with baby formula, a baby toy, and many brochures filled with valuable coupons for free or discounted baby items. On my first prenatal doctor's visit I was given a box of free items, i.e., calcium tablets, vitamins, etc. On each proceeding visit I had a choice of other free items and magazines with valuable coupons distributed by the doctor's office. I assume I was put on the mailing list with manufacturers of baby products because I am still receiving coupons and free baby paraphernalia in the mail.

In contrast, when we brought our daughter home we were sent on our way with only two disposable diapers and one bottle containing eight ounces of baby formula. The clothes she was wearing the first time she was placed in my arms were taken back prior to departing the Catholic Family Services facility. We received no Gift Packs, free baby items, or discount coupons. Nor were we placed on any mailing lists. The adoption expenses

were not covered by any insurance policy. We were not afforded the same advantages and opportunities as we received when we were birth parents.

The expenses incurred when building a family through adoption are a financial devastation. A small portion (up to $1,500) of adoption fees can be deducted--on personal income tax if the adopted child is considered Special Needs or Hard to Place. Many agencies are no longer placing bi-racial or multi-racial children in this category. My husband and I read about this deduction in an IRS tax regulation on the same page with deduction of gambling expenses. Our adoption expenses included the following:

Initial Registration (non-refundable even if you are turned down)	$ 35.00
Home Study (separate from agency fees and paid with no guarantee of being found acceptable potential parents)	$ 750.00
Pan American Adoption Agency Placement Fees	$1,900.00
Roanoke Catholic Family Services Placement Fees	$3,400.00
Lawyer Fees (to finalize adoption in Courts)	$ 250.00
Medical Costs (physical exams required by Agency)	$ 80.00

We were told the fees charged by the agencies were used to pay for the birth mother's medical expenses, counseling, board and room during pregnancy (if required), foster care for the child, and agency staff salaries. As you can see, family building through adoption is very expensive. Being considered a middle income family, these expenses were hard for us to finance.

When we tell our adoption story to friends, relatives, and co-workers they are appalled to discover the astronomical expenses we incurred to start our family. Like ourselves, they never imagined the adoption of a child would be so expensive!

My husband's employer, USA Today, which is owned by Gannett Company, Inc. has an adoption assistance program. We were pleased and excited knowing that we could receive financial and moral support from an employer. Gannett will reimburse its employees up to $1,500 of expenses incurred when adopting.

Unfortunately, like many other things in this country, adoption is becoming so expensive only the wealthy will be able to afford

it. Although I am able to maintain a good standard of living for me and my family, I know I will never be wealthy working for the Federal Government. Having the good fortune of wealth should not be a prerequisite for becoming a parent. Anyway, no one ever told me you had to be rich to be a good parent!

In light of the above, I hope you will give H.R. Bill 2852, Federal Employee Family Building Act of 1987 your total support. If so, maybe other families will be blessed by God the way mine has. We are hoping to adopt another child some time in the future. Without both our employers' support it will probably be a financial impossibility.

Respectfully,

Kim M. Gore
KIM M. GORE

Martin J. Peters Jr
MARTIN J. PETERS, JR.

HOLLY AND BRYAN PETERS

Mrs. SCHROEDER. Mr. Miller, would you and Benjamin like to testify?

STATEMENT OF LAWRENCE M. MILLER, ACCOMPANIED BY BENJAMIN

Mr. MILLER. Well, Benjamin is not talking this morning.

I am here, also, in support of your proposal, and testify particularly with respect to the part of the proposed bill that would cover fertility treatments and in vitro fertilization. Infertility is, as has been established, a health problem affecting millions of couples, and it affected us. It has profoundly affected our lives, and I testify from a personal perspective.

My wife and I went through 3 years of infertility tests and treatments, and it was 3 years of waiting and hoping, wishing and envy and jealousy, and not knowing what would happen next. It was a very, very emotional period, a period during which, as my wife puts it, we were paralyzed by sadness much of the time—it becomes impossible to go through the streets and see pregnant women, watch the news and see stories of unwed junior high school women—family gatherings can become difficult.

My wife at one point just was not up to attending a baby shower of one of her best friends, just because of the emotions that were involved. It was a very, very difficult period. And we, nonetheless were determined to have a baby.

My wife underwent several invasive fertility tests, including a test that established that her Fallopian tubes were blocked by scarring. She then had a lengthy microsurgery to remove the blockage and she became pregnant almost immediately. We thought things were just wonderful, but they weren't. That is not where Benjamin came from, because the pregnancy turned out to be an ectopic pregnancy, the embryo was developing in one of those scarred tubes, one that had been repaired, rather than in the uterus. And the tube eventually ruptured.

At 5 one morning I heard a loud thud, it turned out to be Maureen falling over in the hallway, hemorrhaging internally. We rushed to the hospital and she was saved, but the embryo, of course, was lost and we were starting over.

We were told that the remaining tube was very unlikely to produce anything other than yet another ectopic pregnancy. It was the bad one that was left and the so-called good one was gone.

My wife is a commissioned officer in the Public Health Corps, a nurse by background. And these fertility treatments were performed as part of her health benefits in military hospital facilities in this area.

The proposed legislation, as we understand it, would ensure such coverage to civilian Federal employees. Or even for couples whose health care coverage does take them up to the point we had then reached, help generally ends.

There are options for having a family at that point, there is adoption, there is IVF, there are other techniques, but the out-of-pocket costs are enough to stop many families from proceeding further.

Despite the setbacks we had experienced, we were intent on having a biological child at that point. We were looking at other alternatives, also—there are other alternatives that were acceptable, but that was our preferred alternative.

This was to be our first child, we had married fairly late in life, I was pushing 40, I am pulling it now—my parents didn't have a grandchild and this was probably their only chance to have one. And we were guided to in vitro fertilization. That is the procedures in which the fallopian tubes can be circumvented by removing eggs from the wife's ovaries, fertilizing them with the husband's sperm in a laboratory, and then just 24 or 48 hours later, reintroducing the resulting embryo, if there is one, into the wife's uterus.

The concept is simple, the procedure is very complex. It involves all sorts of complicated medical determinations with respect to hormone levels and a number of factors. It involves specialized fertility drugs that are administered daily for extended periods, counting the period before the conception took place and afterward, when we were lucky to have a pregnancy to nurse along.

I think I gave my wife shots something like 65 or 70 days in a row. It involves careful monitoring, many, many trips to the clinic. And in our case, a surgical, medical procedure, although most IVFs are still being performed, we understand, with a surgical procedure. There is extraordinary discomfort for the woman involved.

As I said in here, it is not an attractive alternative to the normal inception of pregnancy, no one need fear, I assure you, that couples are going to go off and try IVF and ask for it to be paid for by their health benefits, who could use any other way to achieve pregnancy.

It is an emotional roller coaster, and I saw looking through other testimony that is to be presented today, that's the common term, it really is the best way to describe things. But it does offer a reasonable hope for success for childless couples who are willing and able to try it.

There is a success rate currently, we understand, of approximately 50 percent, if a couple is able physically and emotionally, and financially to try the procedure at least three times. That success rate has improved sharply over the past several years, as you would expect with a fairly new procedure which is being used more and more often.

IVF was originally an experimental treatment, it is now classified as a experimental treatment. It is a treatment which corrects a health problem, it allows the body to function normally, despite the symptoms or problems caused by disease, or physical health problems.

We underwent one IVF procedure, it cost us approximately $4,000. Military health facilities do not perform that procedure, so our military health coverage was at an end at that point. The Public Health Corps will not pay for the procedure to be performed at civilian facilities. My private insurance did not cover IVF. Some of our neighbors have coverage which is written in the State of Maryland, Maryland requires IVF to be covered, along with other fertility treatments. We didn't have that advantage in the District of Columbia.

We were very lucky, we could afford to try the program without insurance assistance. Others we met though in the waiting room

told us about the problems they had had in putting together the $4,000 for one try—people who had put together everything they could, borrowed from family, borrowed from friends, gone in hock to try the procedure once and didn't expect to be able to try it again.

There are many other couples, obviously, who could never be in that waiting room, couples who couldn't put together the money for even one IVF try. We have spoken to several civil service employees, as well as members of the military, who had reached a dead end. They had had the testing, they had had the procedures, they knew IVF was their final hope, they couldn't afford IVF.

A good start to providing an opportunity for such couples would be for those treatments, along with other treatments for infertility, to be added to federal insurance programs, so that the cost of this life-creating procedure could be spread over a large group of insureds. That's what health insurance is all about.

The federal government could be, and we believe should be the leader in focusing attention nationwide on the sensibility of such coverage.

Having children is of course a fundamental part of every society. Helping couples financially who face medical problems in having children through mandatory group insurance coverage of infertility treatments would responsibly address a serious health problem and benefit society.

Our story, obviously, has a happy ending, and he is sitting here. We underwent the IVF treatment in May of 1986, and in January of this year, our son was born. He was six months old yesterday. We knew all along, theoretically how great it would be to have a child, we just couldn't imagine though what it was really like. We are very, very lucky people, and we wish that others could be covered by this insurance and be as lucky.

Mrs. SCHROEDER. Thank you.

And now let's finish the panel with Administrative Law Judge Robert E. Sears.

Welcome.

STATEMENT OF CHIEF ADMINISTRATIVE LAW JUDGE ROBERT E. SEARS, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY LEEANNE SEARS AND ASHLAND VICTORIA

Mr. SEARS. Thank you very much.

I hope you recognize it is not very easy to address this subject for those of us who have been through it without becoming emotional. It is a very powerful emotional experience. My wife is here with me, and I am going to try to speak for her, with her feelings, although I don't fully experience them, obviously.

We, also, have a happy ending. And I will say that for the price emotionally and cost-wise we paid for our new daughter, we would do much more than that. It is worth it. And we are happy to have her in every respect.

To say that this is an emotional roller coaster, I think is an understatement. I have watched my wife and other women be in this position—talented and successful as they might be, and yet constantly be fighting the feeling that they are inferior as women.

That they are not able to become complete as a woman, or as a human being. And no amount of success that is taking place in the world seems to be able to overcome that.

And it is something that is not only difficult for the wife, it is obviously difficult for the husband as well.

I am not going to try to speak entirely for her feelings on that matter, let me talk to you about the feelings of a husband that, because of his chosen vocation, is forced to conclude that he cannot afford to give her the things that she wants the most, and that is a family. To feel that I have the choice to either sacrifice everything that I have worked for, or on the other hand, elect to become and remain childless for the rest of our lives, is simply an untenable choice.

I want to make the point that I haven't any reason to complain. The salary of an administrative law judge is well-known, I earn something close to $8,000 more a year, in addition to that, from Reserve activities, mostly in your home state of Colorado, as a matter of fact, which I find to be a lovely place.

But for us the $11,000 that we spent over the course of a year in attempting infertility treatment, in vitro fertilization, and ultimately adopting was a tremendous struggle. And I simply think to myself what does that mean for the lower level federal employee. I can afford it, we can make it by struggling through, but what about the GS-4, shouldn't the GS-4 or 5 have the same equal access to infertility treatment, and ultimately adoption as I?

I felt myself, as did my colleague here watching people going through the program, some of them truly didn't have a struggle meeting the costs. They could afford to do it, and not sacrifice anything.

On the other hand, there were others there that were putting together virtually everything they had to be able to make a try.

Now, I am not forced with that kind of choice in normally deciding whether I should seek health treatment or not. Generally speaking, if I contract some sort of a disease, I don't have to decide that I am either going to seek treatment and let my family and all my resources go down the drain, or on the other hand, I am going to just decide to preserve the resources that we have and preserve our home and preserve an opportunity to educate my child, and simply not decide to be treated.

That's really the choice we are placing before people who have infertility problems. To say this is something that will just go away, that just get involved in your career, or get involved in your community and you will forget about your infertility is a joke. It doesn't work that way, and to make someone either decide to be childless, or on the other hand, to decide to sacrifice virtually everything for the opportunity to overcome this problem, I think is a cruel choice. It simply is unconscionable to do that, and we do not do that in medical procedures, generally.

We are all aware that there are expensive procedures, some of them that even involve some amount of choice with the individual. But yet the choice as to whether to do it at all, but yet we don't hesitate in saying that those are procedures that ought to be covered, so that the individual doesn't have to figure out someway to come up with $10,000 or $15,000 for medical expenses.

And my point—and I have talked to federal employee after federal employee, and let me mention in closing the military. The military has no choice at all. CHAMPUS either pays for procedures, or does not pay a procedure, as you know. And military members have called me and said "What can we do? We don't go outside to get private insurance, and there is no option for us to choose, so we are stuck with whether CHAMPUS will pay for it, or not pay for it."

Essentially, federal employees are in the same position, we can't afford to go out and contract on an individual basis for health insurance policy. We simply have to decide among the policies that are available to us. And presently all of the policies specifically by wording, exclude in vitro fertilization, as you know.

[The statement of Mr. Sears follows:]

Testimony of the Honorable Robert E Sears

Before the Subcommittee on Civil Service of

the Committee on Post Office and Civil Service

United States House of Representatives

July 23, 1987

Madame Chairman, I deeply appreciate the opportunity to speak before you today concerning what has been, for both my wife and myself, a burden of the heart for over 11 years. Needless to say, I appear here today as a private citizen and do not represent the official views of my agency.

For more than 17 years, my chosen vocation has been one of service to the United States. I entered the United States Air Force in 1970 during the Vietnam War and served over four years as a judge advocate. I left active military service to be appointed as a United States Administrative Law Judge for the Department of Health and Human Services (then the Department of Health, Education and Welfare), Social Security Administration, and have served in that capacity through the present date. I currently serve as Chief Judge in Norfolk, Virginia, and my primary responsibility is to hear and decide Social Security disability and Medicare appeals, cases essentially similar to those in which you and colleagues frequently express interest when they involve your constituents.

I applaud your courage in introducing the Federal Employee Family - Building Act of 1987 and your sensitivity to the enormously painful matter of infertility and its insidious financial implications. My intention is not to provide you with a scientific, legal, or statistical rationale for this legislation; rather, I represent the thousands of couples who have experienced the pain of childlessness first-hand, who have shed more tears than they care to publicly acknowledge, pursuing a biological function most couples take for granted or ever try to prevent. For us, it isn't a matter of family planning, waiting until the opportune time in our lives. It is a question of how, not when.

In 1975, less than six months before we were married, my wife underwent emergency surgery for what was suspected to be a pelvic tumor. Instead of a tumor, her surgeon found a massive pelvic infection of obscure cause, and would have performed a hysterectomy had it not been for the fact that my wife had been his patient for a number of years and he felt uncomfortable removing all her female organs at the age of 20 years. He candidly explained to both her and myself, however, that the likelihood of her having children was remote. Over the next five years, my wife and I dealt with her infertility primarily through denial. Even though we were well aware of the effect of her infection, the fires of hope continued to burn and in the recesses of our hearts, we believed that somehow the seemingly impossible might still happen. It didn't.

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In early 1981, my wife was referred to an infertility specialist in Richmond, Virginia and surgery was recommended. Through a physician friend, I obtained a referral for my wife to Dr. Howard W. Jones, Jr., at the Department of Reproductive Medicine of the Eastern Virginia Medical School in Norfolk, Virginia. My wife, Leeanne, and I both felt gratified to be associated with what was becoming recognized, even at that time, as one of the world's premiere infertility research centers, and our optimism rose. During the next several years, we entered a world of scientific testing and study that we previously were not even aware existed, and tests like the endometrial biopsy, post-coital study, sperm cross-matching, and the like became old friends to us, not to mention the procedure which is the bane of infertile couples, the basal temperature chart. Two surgical procedures followed, each with its cautiously optomistic promise of success and each with its heartbreaking failure. Finally, it became apparent to all concerned that in vitro fertilization was the only option remaining medically, and a surgical laparoscopy was performed to screen my wife's candidacy for the procedure.

We experienced several emotions at the point that in vitro fertilization was being considered. On one side, there was a feeling of relief that, even though everything we had tried had resulted in failure, nevertheless, there still remained something that at least held out the possibility of success. On the other hand, we both wondered how much more failure we could withstand, not to mention the financial burden the procedure would impose. I think it's fair to say that we looked at the road before us with some fear and trepidation, but at the same time we recognized that this might be the only way to fulfill our dream of having a child. We decided to go forward.

Several months before my wife's laparoscopy, when we could see the possibility of in vitro fertilization coming, I called the home offices of my federal health insurer because the clinic staff had informed me that most insurers were refusing to cover in vitro fertilization as a medical expense. I talked with a staff member of the company, who decided to check out the matter with her superiors and call me back. She called back, indicating that her superiors believed the procedure would be covered and that we should go ahead with it. A few months later, when we were getting ready to do the laparoscopy, and thinking about scheduling an in vitro fertilization attempt, I called the insurer again and was told that the procedure would definitely not be covered based on the fact that it was "experimental". I can't tell you how many subsequent telephone calls I made to the insurer in protest, and I spent one night in my office until almost midnight going through every shred of paper in my files trying to find the written note recording the events of the telephone call months earlier. I couldn't find it, and I felt that my only hope of holding the insurance company to an earlier position was now gone.

At that point in time, 1983, only one federal health insurance carrier was specifically excluding in vitro fertilization in its coverage. The rest, like my company, chose to deny benefits based on the "experimental" nature of the procedure or, more insidiously, on the basis that the procedure did not "correct a bodily malfunction or illness". It turned out that my wife, after the laparoscopy, was not a suitable candidate for in vitro fertilization, since her one remaining ovary could not be reached by the traditional method

due to adhesions she had formed from her multiple surgeries. For us, this was the apparent end of a road we had traveled some eight years, and was one of the low points of our married life.

In the several years that passed after our case was medically closed, we rode an emotional roller coaster. We checked one adoption agency after another, only to find that most would not even take our names onto their waiting list, and the few that would had costs ranging from a low of over $6,000 to a high of more than $15,000. Even though we knew it would be a financial struggle, we nevertheless pursued adoption and, as medical science progressed, the Jones Institute discovered that a new procedure, a trans-vessicle approach, would finally give my wife an opportunity to attempt in vitro fertilization. In January of 1986, we began the process of attempting to have a biological child through that method. By that time, every federal insurer had specifically worded its health coverage policy to preclude payment for in vitro fertilization or similar infertility expenses, but, despite the cost, we felt we had little choice except to give the procedure a try.

There is no way to adequately convey to you the feelings of an infertile woman. For my wife, as beautiful and talented as she is, there was a constant feeling of inadequacy and incompleteness as a woman. Even though her biological function was something that she could not voluntarily control, the knowledge that she could not perform a function inherent to her womanhood and taken for granted by many women was, at times, almost too much to bear. This is not a matter of logic; it is a burden of the heart. Many women can make a

rational choice and elect not to have children for personal reasons, but for a woman like my wife whose dream from the days of childhood was to be a mother, no amount of reasoning can overcome the pain caused by the probability that the dream will likely never come true. Over the years I have seen my wife and countless other women who are strong, courageous, and talented struggle to carry on their lives amidst the constant feeling that they are failures as women and human beings. I have seen them alternate between crying their hearts out, pleading with God, and doggedly pursuing medical and adoptive procedures, refusing like the Biblical Rachel to be consoled. Make no mistake: even for the strongest couple, the physical and financial obstacles of infertility can be devastating, a storm unlike any they have ever encountered before.

Up to this point, I have primarily discussed the pain of infertility from the viewpoint of a husband who is both a part of the couple and the best friend of the woman who is suffering and desperately searching for a solution. To say that this is a consuming process is an understatement; indeed, it becomes the driving force of your life, a hunger refusing to be satisfied. For us, there was a requirement for courage, emotional fortitude, and sensitivity to each other unlike anything else we had encountered in nearly 12 years of marriage. There were times when the emotional strain was almost too much to bear, and, in my own opinion, a couple without a great deal of stability in their marriage, loving support from family and friends and a foundational faith in a loving God would simply be unable to withstand the pressure.

But I also carried a burden that my wife did not bear, one caused by the constant search for a way to overcome the financial mountain of infertility. Let me make it clear to you that I have no reason to complain about my financial status. As a United States Administrative Law Judge, my salary approaches $55,000 per year, and I have remained an active member of the United States Air Force Reserve with the rank of Lieutenant Colonel. The reserve activities provide me with roughly $8,000 per year in additional income, so my combined income of roughly $73,000 per year exceeds the pay cap of the general schedule and is not far from the salary paid to Members of Congress. We do not live extravagantly, and at the time the infertility expense burden became the greatest, both my wife and I drove automobiles approaching ten years in age.

I don't think that I can adequately communicate to you the despair and feelings of inadequacy of a husband who finds that he has to deny his wife the one thing in life she wants the most, a chance to overcome the burden of childlessness, simply because he doesn't earn enough income to meet uninsured medical costs. Nothing in my life has ever weighed on me so heavily. For nearly a year prior to the point that we actually began an in vitro fertilization attempt, I postponed one scheduled attempt after another because we simply could not find a way to pay the $5,000 medical fee. I was attempting to sell our home and our debt primarily from our home mortgage was too substantial to permit refinancing, so the situation for us was financially hopeless. I scheduled one attempt after another, hoping that the home would sell, and finally when the burden became too great for my wife to bear, I

persuaded a bank officer to let us extend our debt beyond normal limits on a short-term basis and this provided the money for us to make the attempt.

Let me tell you what the attempt was like. Leeanne, who had for 11 years struggled to find a way to conceive, finally had her chance. It was as though she had been sitting on the bench for years, desperately wanting to get into the game, and now it was her turn to bat! Each phase of the process brought with it the sweet taste of a hard-fought victory: her eggs matured; the surgical procedure, though unusually difficult, yielded one healthy, mature egg; the egg fertilized beautifully. Finally, it came to the time to transfer the egg into her uterus, and she was riding on the clouds.

I'll never forget my own feelings driving into the hospital that day. I looked at the building and thought to myself, "Somewhere in a room deep in the bowels of that building is a tiny person, our baby. We're actually going over there to pick up our little son or daughter." I'll never forget it as long as I live. And my wife? For the first time in her life, she had a life growing inside her. How can I possibly describe the depth of those feelings? It was unlike anything we had ever experienced.

But our little son or daughter died. Whether it was within hours or days, we'll never know; but in the pain of that death, we still were grateful to have come so far. We had our chance. We had gambled and lost, and there was no more money to try again. But God did a miracle for us, and a few months later, our new adopted daughter, Ashland Victoria, came home to live with us

on November 7, 1986, the happiest day of our lives. With her came a price tag of nearly $7,000, a bill I had no way to pay, but in the exhilaration of those days, we didn't care. Miraculously, God intervened and our home was sold only a few weeks later, giving us the resources to pay the adoption fee.

Madame Chairman, my argument is this: if a Federal employee at or near the top of the general schedule pay level must struggle to afford to meet basic family- building costs either from medical procedures or adoption, what then is the position of the GS-4 or even GS-10 employee who should have an equal right to pursue a solution to childlessness along with the financially secure? It was obvious to me as I looked around at the group going through in vitro fertilization with us in January 1986 that many of those families had income levels higher than mine. For them, the financial considerations were probably a burden, but one that could be borne. Others were there only at great personal sacrifice. There was one lady there who could not have afforded the procedure at all had it not been for the fact that her insurer was paying the bill. She was a State clerical employee from Maryland, and she was able to attempt the procedure because a Maryland statute provided that all insurers doing business in the State of Maryland were required to cover infertility expenses including in vitro fertilization. It's time we provided the same protection to Federal workers, be they clerical employees in Maryland, military personnel in Colorado, or Administrative Law Judges in Virginia. After all, the primary reason for medical insurance is to provide protection against expenses that otherwise would plunge a family into financial disaster. I obtain health insurance so that if disease or illness strikes, I

won't have to sell my home or risk losing everything I have to pay for medical care, yet our insurers continue to deny coverage for most infertility expenses, putting Federal employees like myself in untenable financial positions.

As a Federal employee, I only have the option of selecting among the various plans offered to me. To contract as an individual for health protection would be prohibitive, as we all recognize. But why, I ask, is it unreasonable to pay for medical procedures designed to correct infertility? If I contract cancer or heart disease, I am not required to choose whether I should go into debt and obtain treatment or alternatively elect not to be treated at all, avoid the expense of treatment and preserve my resources for the benefit of my wife and daughter. That is precisely the choice we place before infertile couples through the Federal health insurance plans. To require Federal workers to choose between a life without children (even though a potential way to resolve that problem may well be available to them) or a massive debt load to pay a medical expense is more than cruel - it is unconscionable. I know what it feels like to be faced with those choices, and it is an emotional nightmare.

Over the past year, my expenses trying to have a child exceeded $11,000. My suspicion is that virtually every Federal employee and indeed Members of Congress that did not have some sort of independent financial income other than their salary, would find it exceedingly difficult to meet that sort of expense. I have first-hand knowledge of how it affects some Federal

employees, because, since my involvement with the Jones Institute for Reproductive Medicine in Norfolk began, I have let it be known to the administrative staff that I would be happy to serve as a point of contact for individuals, particularly Federal employees, who are frustrated about the lack of insurance coverage for infertility expenses. As you undoubtedly know, all the Federal health insurance carriers have specifically exempted in vitro fertilization and similar procedures from their coverage by direct language, and most have gone even further and eliminated virtually any expense relating to infertility. This is a tragic and unjustifiable position, one which must not be allowed to continue. I have had virtually weekly telephone calls from angry, frustrated Federal employees across the country inquiring whether anything can be done to solve this situation. Each one has been in the same financial position: an IRS agent from New Jersey; an Army sergeant from Virginia; a research physician in Louisiana; a clerical worker in West Virginia, to name just a few. Each one has openly expressed his or her concern that the medical expenses of an uninsured procedure are simply prohibitive, as are even adoption expenses in many instances.

Madame Chairman, we cannot continue to tolerate a situation where a solution to childlessness is available either primarily or exclusively only to the financially secure. The devastating feelings of inadequacy and frustration and the consuming, overwhelming desire to find a solution are not restricted to couples of certain races, educational levels or religious preference. Like disease, infertility reaches across ethnic boundaries to wreak its emotional havoc. In a society that has prided itself on its advances in equal

opportunity and treatment of all its citizens, I am compelled to argue that we as Federal employees deserve the right to engage in family-building procedures equally with those who work in the private sector, many of whom have insurers who cover their infertility expenses.

While there is no way to legislatively relieve all the pain and frustration of infertile couples where that pain is caused primarily by one failure after another, I sincerely hope as one who has been there that Congress will aggressively promote family-building procedures by easing the financial burden and opening the door to those who could not otherwise continue their quest for a solution to their infertility. The bottom line is that medical costs related to infertility procedures, and even adoption expenses themselves, prohibit most Federal workers from pursuing those options except at great sacrifice. I believe, as many others do, that the strength of our society will continue to be built from the nucleus of a strong family unit and, indeed, we should promote any effort that will build loving, stable families. In my case, as difficult as the road has been, my marriage is strong and I have a daughter who has provided more joy to my wife and myself than we ever imagined possible. In one sense, I have no complaint. She is worth every sacrifice we made, and more. The cost of obtaining her was roughly that of a moderately priced new automobile, and to us, she is worth more than a hundred automobiles. But at the same time, I shudder when I think that there are Federal employees who love this country as much or more than I and who have served it faithfully, but are, at the same time, denied the deepest desires of their hearts simply because their salary level is not adequate to meet an

additional financial burden of $5,000, $10,000, or more. We ourselves will shortly again face the choice of balancing our resources between the difficult options of providing for Ashland Victoria's current needs and future education or obtaining a new little brother or sister for her.

On behalf of those employees, who wrestle with the choices of whether to sell everything they own, mortgage themselves close to the point of disaster, or alternatively simply find a way to live with the knowledge that they will always be childless, I call for an end to the unjust and unfair practices of the Federal health benefit insurers that deny reimbursement for infertility procedures and I strongly urge a commitment by this Congress to family building. I can think of nothing that would exert a more positive effect on our nation for generations to come than the encouragement of procedures that will build stable, loving family units.

Thank you very much.

Mrs. SCHROEDER. I want to thank the panel.

One of the things that I think is so important to emphasize is that you are all saying, "Look, we should have coverage for either way of building a family, whether it is through infertility treatments, adoption, or both".

Right now we are discriminating tremendously, in that the only kind of coverage you have is if you do it in the regular way. Everything else, you pay very dearly for.

I think the U.S.A. Today story about American families is very sobering, that the economic condition is such that in almost every family, both people are having to work. And just to get a car and a house. I think your point is very clear, many are going to be denied the option of having children, if this cost is not covered and spread widely, so that everybody shares it. The costs of everything have just gone up way beyond how people's salaries have.

I want to compliment all of you for your very touching statements. We truly appreciate it.

Thank you all for being here. And beautiful babies.

Let me call up the next panel, Dr. Alan DeCherney, who is the John Slade Ely Professor of Obstetrics and Gynecology, at Yale University School of Medicine, in New Haven. Dr. Nancy Alexander, also a professor of obstetrics and gynecology at the Jones Institute in Norfolk, VA, and Dr. Maria Bustillo, reproductive endocrinologist, Genetics and IVF Institute, in Fairfax, VA.

We welcome you all this morning for your expertise and your view of what is transpiring.

And, Dr. DeCherney, why don't we start with you?

STATEMENT OF DR. ALAN H. DeCHERNEY, JOHN SLADE ELY PROFESSOR OF OBSTETRICS AND GYNECOLOGY, YALE UNIVERSITY SCHOOL OF MEDICINE, DIRECTOR, DIVISION OF REPRODUCTIVE ENDOCRINOLOGY

Dr. DECHERNEY. Thank you for inviting me. And I would just like to give an overview, I guess some statistics and some of the things that we deal with on an every day basis with regards to the treatment of infertility. 8.5 percent of married couples between the ages of 15 and 44 are infertile. That means that there are 10 million infertile people in the country, and there are 5 million infertile couples.

It has been reported that 1 million new patients present for infertility problems in any 1 year. That makes it 4 times more common than diabetes, it makes it 20 times more common than AIDS, and it make it 500 times more common than patients with cancer of the lung.

In 1986, the expenditure for infertility procedures, both diagnostic and treatment, approached $935 million, of which 30 percent went for medical, MD costs, per se.

Infertility has become in the past few years, a very compelling problem. My own feeling is this is probably because of the lack of babies for adoption. The number of babies for adoption has decreased precipitiously in the past decade, and this is for a number of reasons. One is the appearance on the scene on therapeutic abortion, the appearance on the scene of better contraception, young

women keeping their babies, rather than giving them up for adoption, the stigma of having a child out of wedlock is no longer as great as it used to be.

And, of course, the increased cost of adoption, especially for underprivileged people, it has become a prohibitive expense.

Infertility also has become a new kind of interest to people, a lot has to do with media coverage, it is hard to pick up the paper, as evidenced by your comments just a moment ago, that doesn't have something to do with reproduction in some way, or form. So, it is a very commonly discussed issue in the press, and it is something that we hear about alot. And patients are very well educated.

The patients are now demanding infertility care in large numbers.

The other reason I think that there is a growth in infertility treatment, or need for infertility is that we can do something for patients now. The cure rate for infertility, after the Second World War, 40 years ago, was 25 percent, it now approaches 75 percent.

There are some social issues at hand, one is delayed child-bearing, and increased women in the work force. Another is there is an increased rate of infection, this is especially true in poor populations, pelvic inflammatory disease that causes patients to be infertile is on the increase.

There is a difference between infertility and sterility. Infertility are patients that can't get pregnant and need help. Sterility occurs in patients that are infertile, but for irreconcilable reasons. And the infertility rate is given at about 10 percent, or 8.5 percent of the population. The best way to express it is that 100 healthy couples check into a hotel, and they are not allowed to check out of that hotel, until they have conceived; 15 patients, or 15 couples will check out each month for the first six months, so 80 to 90 percent of the patients will have conceived, another 10 percent will conceive in the following 6 months. And after one year of unprotected intercourse, that really defines the infertile population.

It is a serious and overwhelming disease for people, as you know, mainly surrounding the lack of having children. The actual work up and treatment is not a pleasant course, it is surrounded by a number of side effects. But I think that if patients could be given a guarantee that they would go on to conceive, these aspects of the infertility work up are tolerable.

But the fact that these patients have tremendous psychological trauma, certainly has to go into our formula of understanding what is going on here, as far as the. societal and the health issue.

First, they mourn the loss of personal growth, there is tremendous personal growth associated with having children, and these people are denied that. They are spared the pleasure of raising children as a couple, I think it is an important part of the life of a couple to have children and also, what we get to see in older people, is a tremendous loneliness because of the lack of companionship of having children.

The work-up costs between $1,000 and $2,000. It includes for the woman—and I won't go into any great detail—tests of ovulation, tests of cervical factors, and tests that her tubes and the remainder of her anatomy is normal. For the man, essentially, the work-up is

a seman analysis. There are other tests and I am sure the other panelists will go into some detail about these.

The treatment of infertility is roughly $1,500. If you look at all kinds of treatment, it is roughly $1,500, so we are looking at, for an uncomplicated case, $2,500 is the cost of an infertility work-up and treatment. Other treatments are very expensive—the use of Pergonol, a drug that we commonly use costs about $1,000 per cycle, and many patients take up to four cycles to conceive on that. So the total can be $4,000.

Operating on patients for diseased Fallopian tubes costs about $5,000 including the fee for the operation and the hospital costs. Donor insemination has become very expensive, now that we have to freeze sperm and have to screen donors for AIDS, and that now costs $1,500 per attempt at AID not per cycle. And in vitro fertilization, which has become the most controversial area, is approximately $5,000 per cycle, in most centers.

Insurance coverage is spotty, part of the reason that we are here today. And my knowledge of insurance coverage is sketchy at best, but every time I have had any dealings with insurance companies over this, they have the same cry, that they are only interested in cause and effect. If you can prove a cause for infertility, like a pelvic infection, then they are not anxious to pay for it, but they are willing to pay for it.

But if the patient is infertile and there is no reason, the reason is that she doesn't ovulate, then they are not happy to pay for it.

And the example that I gave in my written prepared statement is that if a patient doesn't ovulate, insurance companies will not pay for her coverage. But if she has a car accident—and we can remotely tie that car accident to her inability to ovulate because of a concussion, then they are sometimes willing to pay. That kind of fuzzy, remote thinking certainly makes it very frustrating for people that deal within the field.

HMO's are fairly consistent, they exclude payment for infertility, almost across the board. And this is for any number of reasons, I think the major reason is that they don't want to pay for the successful treatment, and that is to pay for care for OB, obstetical care and pediatric care.

From a cursory look at the figures, as far as federal employees, it looks like there are approximately 50,000 couples in the federal system that suffer from some form of primary, or secondary infertility. It is a major life crisis for these patients, especially the poor. It requires two special kinds of care, different than other things that we do as physicians.

One, there is a tremendous need for psychological support, this is costly and inefficient, this is not readily available to the poor. And another, and most important thing is continuity of care. It is important for infertile patients to see the same doctor time after time. It is not very good to fragment this kind of care, it doesn't seem to work well, the success rate is decreased if the care is fragmented. And certainly this depends on the amount of money that people have to pay for their care, if they are to get continuity of care. The less money you have, the less continuity—that has been shown in almost every field of medicine.

So, patients need acquisition, this depends on education of the patients, the availability of the care, and the financial ability for patients to pay.

One interesting study by Hersch and Masher, published in Fertility and Sterility in April 1987, showed that looking at just educational level, in patients that completed a high school education compared to patients who didn't complete a high school education, 94 percent of the patients that presented with infertility had completed a high school education. Certainly indicating that there is some real social value system at work here that selects these patients.

So, in summary, having a family is a basic human want. The inability to have a family is as painful, and as serious as any disease known to man, or women. And since this affects young people, the pain is of much longer duration, and perhaps of greater magnitude.

As physicians and a society, I think we are obligated to lighten the burden of these unfortunate couples through better health care, higher quality research and most importantly, through financial support.

Thank you.

[The statement of Dr. DeCherney follows:]

Statement to the U.S. Congress

Alan H. DeCherney, M.D.

Infertility is a problem of national scope. It affects approximately 15% of couples in the United States in the child bearing age group, representing approximately 10,000,000 couples or 20,000,000 people. Recent changes in health care have made infertility a more compelling problem. In the past babies were available for adoption in order to solve this life crisis. Now, with single women keeping their infants, and the appearance on the scene of therapeutic abortion on a large scale these babies are no longer available for adoption. The increased cost of adoption has also made this not a viable alternative for the poor. This has compelled patients to find medical help in order to treat their infertility. The statistics indicate a large increase in the volume of infertility practice in the last few years. A good portion of this has to do with better education of the public; in the past patients were unaware that infertility was a treatable disease.

Other problems have become important in regard to infertility. One is the delayed child-bearing of women. Since it has been well documented that fertility begins to decline at age 35 this has caused a rise in the infertility rate and impacted on the workforce as women are forced to make a choice between career and child-bearing.

Infertility is caused by the male factor 40% of the time, the female 40% of the time and 20% of the time it is a couple problem, with both the male and female having problems of sub-fertility.

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Most couples view infertility as a major life crisis, and as devastating as any disease possible. They mourn the loss of personal growth through child-rearing, the shared pleasure as a couple in having children, and the loss of companionship of children. Infertility patients are frustrated, desperate and panicked by what they perceive as the loss of control. In addition to the effective, yet relatively expensive, medical care available these patients require costly social and psychological support as well.

The work-up of the infertility patient involves a thorough history and physical, with special attention to specific implications, i.e. exposure to toxins, sexual adjustment in the marriage and chronic illness. This is followed-up by a semen analysis on the male that looks at the number of sperm he produces and the ability of those sperm to swim in a progressive fashion. In conjunction with this, the first prerequisite for the woman is that she produce an egg each month. In conjunction with the production of the egg, and as a marker of this event, a hormone, progesterone, is produced starting at mid-cycle. The presence of progesterone, indicating that ovulation (egg production) has occurred, is marked by measuring either a change in basal body temperature or by measuring progesterone levels in the blood. If the sperm count is adequate, and the woman is producing eggs, the next test performed is a post-coital test. In this test the couple has intercourse and two hours later it is assessed whether sperm are getting through the cervical canal to begin their assent into the uterine cavity to the fallopian tube, where fertilization occurs. If the post-coital test is normal the next test in the schema is a hysterosalpingogram. This is an X-ray of the patient's fallopian tubes to make sure that infection has not

caused them to be closed. If this is normal the last test in the work-up of the female is a laparoscopy. This is an operative procedure performed under general anesthesia where a periscope is placed through the patient's navel and her pelvic organs are inspected for evidence of abnormality. This includes inspection of the uterus, tubes and ovaries. A frequent finding in this examination is the presence of endometriosis, a common cause of infertility.

This is a proposed, step-wise work-up of patients, rather than doing all of the tests at once. Although prolonging the work-up, this is a more efficient way to get to the proper end-point: diagnosis.

Once the disease entity is identified by an abnormality in any of the diagnostic tests that make up the basic work-up, proper in-depth evaluation and treatment is indicated. If the sperm count is abnormal then perhaps intrauterine insemination, placing sperm inside the uterine cavity, will be effective. On the other hand, if the man makes no sperm at all, then donor insemination is a possibility. If the woman does not produce eggs, then agents to induce ovulation are used, the common ones employed are clomiphene and Pergonal^{R}. If there is a severe underlying endocrine disease, i.e. thyroid disease, then this must be corrected before proper ovulation can be assured. If the after-intercourse test is poor, then the patient must be evaluated for the production of sperm antibodies. If the tubes are damaged, then surgical correction or in vitro fertilization would be the treatment of choice.

The field of reproductive endocrinology and infertility has seen a burgeoning in the last few years of new technology in order to help infertile patients. This has effected a great revolution in what is done, but has also helped to treat a great number of patients. The hallmark event surrounding this is in vitro fertilization. In vitro fertilization is where the eggs are aspirated through either a laparoscopic or ultrasound approach, placed into a petri dish in the lab, mixed with spermatozoa and then the embryos are replaced into the uterine cavity after a given period of time. The technological facts surrounding in vitro fertilization and its compartmentalization of care has added an atmosphere of commercialism to this aspect of infertility treatment.

The insurance industry covers various aspects of infertility diagnosis and treatment. It depends tremendously on the company, on the insured, and more specifically on the policy that is contracted for the individual patient. An interesting aspect of the insurance industry's philosophy in regard to the funding of infertility treatment is that if they can find a exogenous cause for the infertility they are more apt to be willing to pay. An example of this would be if a patient did not ovulate and needed medication they would not pay for it, but if that very same patient was in an automobile accident, had a concussion and this could be remotely tied to her inability to ovulate, the insurance carriers would be more willing to underwrite the bill.

It would appear that legislators are more anxious to insist on payment for coronary artery by-pass than for infertility problems, but this is primarily

because the people that are involved in law-making are more likely to have a coronary by-pass; and, if they have had an infertility problem this is a problem that has been dealt with in the distant past. The funding of research for infertility is also important, not only because infertility itself is a disease, but because better understanding of reproduction and its control will lead to better and more efficient contraceptive measures.

Acquisition for infertility services depends on two factors; one is education and the other is availability. Patients today are extremely well informed about infertility and what can be done for it; so, that arm of acquisition in most areas is not a problem. Some aspect of infertility seems to be mentioned daily in the news. Accessibility, in regaard to care providers, was a problem in the past, but more and more physicians are getting interested in infertility because of the excitement of new ideas, obstetrical malpractice problems, and a fairly lucrative and for the time being, non-threatening way to practice medicine.

Infertility treatment and evaluation requires a continuity of care that is not always available in a clinic setting.

Having a family is a basic human want. The inability to have a family is as painful, and as devastating as any disease known to man; and, since this effects young people, the pain is of much longer duration. As physicians, and as a society we are obligated to lighten the burden for these unfortunate people.

Mrs. SCHROEDER. Thank you very much.
Dr. ALEXANDER.

STATEMENT OF DR. NANCY ALEXANDER, PROFESSOR OF OBSTETRICS AND GYNECOLOGY, DIRECTOR OF APPLIED FUNDAMENTAL RESEARCH, JONES INSTITUTE, NORFOLK, VA

Dr. ALEXANDER. What Dr. DeCherney talked about in his example of a hotel, is a definition of fecundability, the chance that a woman will produce a viable offspring in any given month. Fecundability is strongly influenced by maternal age, it is maximal at age 24, with approximately a 50-percent reduction after age 35.

And yet, as you, Congresswoman Schroeder, pointed out, increasingly greater numbers of women are pursuing professional careers and eschewing childbearing during their most fertile time. As they become older, they are less fertile, and there is less time for them to conceive and bear children. Such couples require rapid evaluation and treatment. The total number of women in the United States who are age 35 to 40 is projected to increase 42 percent. Therefore, the number of desired births will also rise.

As has been pointed out this morning, infertility is a unique clinical situation. It involves both the couple and the individual. About 50 percent can be expected to be treated and cured, for those that are cured as well as those couples who are unable to conceive, despite treatment, the financial and emotional strain can be enormous.

Infertility affects self-esteem, sexual identity, marital stability and life goals. Some of the patients at the Jones Institute say that they feel less adequate than dogs and cats, who can mate and have offspring, whereas they cannot.

We have entered a new frontier for reproductive medicine. And many new techniques are available. We have heard today about IVF; other techniques involve cryopreservation of oocytes and sperm and even embryos. With techniques of IVF, for example, many centers boast a 20- to 30-percent success rate per cycle. Throughout the world thousands of babies have been born by IVF. The Jones Institute has produced 312. Yet, some insurance companies prefer to think of IVF as experimental, even though other companies and even States, recognize the value of this procedure.

IVF is actually a less expensive way to produce a baby than tubal repair. As you heard this morning with our first speaker, even under the best circumstances, the success rate for tubal repair is only about 20 percent, and then there is a high chance of an ectopic pregnancy. The cost of this procedure is $4,000 to $15,000. IVF by contrast, at the Jones Institute, costs $5,600. Since the success rate is about the same with that of tubal repair, and the tubal pregnancy rate is much lower, it is not difficult to see on a simple cost per baby calculation, that IVF is cheaper than surgical repair, yet oftentimes surgical repair, even done twice, will be covered by insurance, where IVF will not. Moreover, it is obvious that the long-term and short-term morbidity and mortality are less, and the loss to society in lost work days is less with IVF.

Is it fair that the new reproductive modalities are available only to the rich, to those with foresight and opportunity, or to those with insurance plans that are more comprehensive?

The administrator of insurance payments for the Jones Institute, Linda Lewis, says that it breaks her heart to tell a sailor that the cost will be too great for him and his wife to avail themselves of IVF, the only solution to their infertility. Such a man is serving his country, and yet he is being discriminated against because his income is too low and his insurance does not cover IVF. The same holds true for many civil servants. Cost also prevents minorities from being provided with the infertility service that they require. One couple sold their house and they used the equity for two IVF attempts, Unfortunately, now they are without a house and without a pregnancy.

As Dr. Sophis Kleegman has said, "Infertility patients are not sick, but they are heartsick, and the help they seek is to them as urgent as any other medical practice". It is only right and appropriate that medical coverage for infertility, including IVF and donor insemination, be provided to federal employees.

[The statement of Dr. Alexander follows:]

Witness: Nancy J. Alexander, Ph.D.
The Jones Institute
The Eastern Virginia Medical School
700 Olney Road
Lewis Hall 2126
Norfolk, VA 23507

My name is Nancy J. Alexander, Ph.D. I am a Professor of Obstetrics and Gynecology at the Jones Institute for Reproductive Medicine, Eastern Virginia Medical School in Norfolk, Virginia. Prior to joining the Institute last fall, I was Director of the Andrology Laboratory at the Oregon Regional Primate Research Center. I am currently the Director of Applied Fundamental Research for CONRAD (Contraceptive Research and Development) at the Jones Institute and I am on the Board of Directors of the American Fertility Society. I have a strong interest in infertility and contraception.

About 3.7 million babies were born in the U.S. in 1986. Yet, one of every ten couples in the U.S. is involuntarily infertile, that is, unable to conceive or bear live offspring. My testimony concerns the fraction of those babies born as a result of medical assistance to those infertile couples. My testimony also concerns the babies who were desired but who could not be conceived or could not be carried to term. My testimony describes the men and women who undergo months and years of medical diagnosis and treatment in order to try to have a baby.

Infertility is defined as the inability to conceive after a year or more of regular sexual relations without the use of contraceptives or the inability to continue a pregnancy to a live birth. Infertility may be classified as primary, when there is no history of pregnancy, or secondary, when inability to conceive

occurs after one or more prior pregnancies. Demographic studies suggest that the chance of a woman producing one viable offspring per menstrual cycle is 20% (fecundability). Life-table analyses indicate that the chance of having a normal pregnancy is about 90% after 12 months when all conditions for conception are ideal.

Fecundability is strongly influenced by maternal age. It is maximal at age 24, with an approximate 50% reduction after age 35. Increasingly greater numbers of women are pursuing professional careers and eschewing child-bearing during their most fertile years. As they become older, they are less fertile and there is less time for them to conceive and bear their children. Such couples require rapid evaluation and treatment. The total number of women in the U.S. who are age 35-40 is projected to increase to 42%; therefore, the number of desired births will also rise.

Infertility is a unique clinical situation; it involves both the couple and each individual. A male subfertility factor is identified in about 30% of cases, a female factor in approximately 40%, and a combined factor in 20%. Ten percent of infertility is of an undefined or idiopathic nature. Appropriate therapy results in a cure in 50% or more of treated couples. Infertility evaluation can take several months, and in conjunction with therapy, longer. Pregnancies may not occur until 6-18 months after a surgical procedure. However, couples

are anxious and apprehensive after only a few months of failing to conceive. The frustration and confusion of the husband and wife are compounded by the costs of evaluation and treatment.

The last two decades of infertility research have elucidated many anatomical, physiological, psychological, biochemical, and genetic abnormalities associated with human reproduction. Treatment can consume years of the couples' lives and thousands of dollars of their savings. For the 50% of couples unable to conceive despite treatment, the financial and emotional strain can be enormous. Infertility affects self-esteem, sexual identity, marital stability, and life goals. Some patients at the Jones Institute say that they feel less adequate than dogs and cats, who can mate and have offspring, whereas they cannot.

We have entered a new frontier for reproductive medicine. Many new techniques are now available. These techniques involve gamete intrafallopian transfer (GIFT), in vitro fertilization (IVF), and cryopreservation of oocytes, sperm, and even embryos. With the technique of IVF, for example, many centers boast a 20-30% success rate per cycle. Throughout the world thousands of babies have been born as a result of IVF. The Jones Institute has produced 312 babies. Yet some insurance companies prefer to think of IVF as experimental, even though other companies and even states recognize the value of this procedure. IVF is actually a less expensive way to produce a baby than tubal

repair: under the best circumstances, the success rate for a microsurgical tubal repair is only about 20%, with a cost of $4,000 to $15,000. One must also add to this cost the subsequent medical care for those patients who conceive a tubal pregnancy following surgery, not an uncommon occurrence. IVF by contrast, costs $5,600 at the Jones Institute. Since the success rate is about the same as after tubal repair and the tubal pregnancy rate is much lower, it is not difficult to see that on a simple cost-per-baby calculation, IVF is cheaper than surgical repair. Moreover, it is also obvious that long-term and short-term morbidity and mortality are less, and the loss to society in lost work time is also more favorable.

Is it fair that new reproductive modalities are available only to the rich, to those with foresight and opportunity, or to those with insurance plans that are more comprehensive? The administrator of insurance payments for the Jones Institute, Linda Lewis, says that it breaks her heart to tell a sailor that the cost will be too great for him and his wife to avail themselves of IVF, the only solution to their infertility. Such a man is serving his country and yet is being discriminated against because his income is low and his insurance does not cover IVF. Cost also prevents minorities from being provided the infertility services they require. One couple sold their house and used the equity for two IVF attempts. Unfortunately, they are now without their home and still without a pregnancy.

As Dr. Sophia Kleegman has said, "Infertility patients are not sick, but they are heartsick, and the help they seek is to them as urgent as any other in the medical practice." It is only right and appropriate that medical coverage for infertility (including IVF, and donor insemination) be provided to federal employees.

Mrs. SCHROEDER. Thank you very much.
Dr. Bustillo.

STATEMENT OF DR. MARIA BUSTILLO, REPRODUCTIVE ENDOCRINOLOGIST, GENETICS AND IVF INSTITUTE, FAIRFAX, VA

Dr. BUSTILLO. Infertility, as you have heard from my colleagues, is a devastating problem to a couple, and it does seem to be on the rise, as Dr. DeCherney pointed out.

What I think is important to remember is that the diagnosis and treatment of infertility requires repeated medical interventions, usually over a period of time of one to 5 years. These diagnostic procedures usually, because they are timed to the woman's menstrual cycle, can take several months and repeated office visits to complete.

Often when a relatively simple problem is found, that problem being amenable to treatment, it is treated for as long as 6 to 12 months. This treatment may result in pregnancy, but however, it may fail, therefore, leading to more invasive diagnostic procedures and testing. The whole process of diagnosis and treatment, and further diagnostic process can be financially very costly and psychologically devastating for a couple.

Couples often feel a lack of control at the failure to achieve a pregnancy, and obviously feel a great financial strain, if they have no insurance coverage. In up to 15 percent of couples medical science to this day cannot presently find an explanation for this infertility. This couple is usually very frustrated, and particularly, if they have insurance that does not cover infertility, and we have no causative effect, we cannot get any medical coverage for them.

Medical and surgical treatment of infertility does result in conception in approximately 50 percent of couples. Therapeutic procedures are aimed at correcting the obvious causative factors. The new and exciting technologies of IVF and GIFT, gamete intrafallopian transfer, are used as treatment when other conventional surgical and medical options have been exhausted. In vitro fertilization candidates have often failed to conceive after repeated, expensive tubal surgeries and they would be unable in the absence of IVF to have their own biologic children.

In order to make these technologies simpler and less risky and less expensive, advances have been directed at making these techniques nonsurgical. By utilizing, for instance, ultra-sound guided techniques, in vitro fertilization can be performed in an out-patient setting without the need for general anesthesia and at reduced costs.

Because the success of these technologies resulting in liveborn offspring is usually only in the order of 10 to 20 percent per initiated treatment cycle, they must often be repeated in an individual couple. This, obviously, is a great financial strain to those who have no insurance coverage.

Thank you.

[The statement of Dr. Bustillo follows:]

HEARING ON H.R. 2852

Maria Bustillo, M.D.
Genetics & IVF Institute
Fairfax, VA

The diagnosis and treatment of infertility requires repeated medical interventions usually over a period of one to five years. Diagnostic procedures, because they have to be timed to the woman's menstrual cycle, can take several months and repeated office visits to complete. When a relatively simple problem amenable to treatment is discovered, it is treated for as long as six to twelve months. This treatment may result in successful pregnancy; its failure may lead to more invasive diagnostic testing and discovery of other causative factors. This whole process of diagnosis and treatment and further diagnostic procedures can be financially costly and psychologically stressful. Couples often feel lack of situational control at the failure to achieve the greatly desired goal of having a child. In up to 15% of couples, medical science can not presently find an explanation for the infertility.

Medical and surgical treatment of infertility results in conception in approximately 50% of couples. Therapeutic procedures are aimed at correcting the presumed causative factors.

The new technologies of in vitro fertilization (IVF), and gamete intrafallopian transfer (GIFT) are used as treatment when other more conventional surgical and medical treatment options have been exhausted. In vitro fertilization candidates have often failed to conceive after multiple tubal surgeries and would be unable to have their own biologic children without this technology. In order to make these technologies simpler, less risky and less expensive, advances have been directed at making these techniques nonsurgical. By utilizing ultrasound guided techniques, IVF can be performed in an outpatient setting without the need for general anesthesia. Because the success of these technologies resulting in liveborn offspring is only 10-20% per initiated treatment cycle, they must often be applied repeatedly in an individual couple.

OVERVIEW OF INFERTILITY

Maria Bustillo, M.D.
Genetics & IVF Institute
Fairfax, VA

Infertility is defined as the inability to conceive after trying for at least one year. Approximately 90% of couples in the U.S. achieve pregnancy in the first year it is desired. There are many causative factors in infertility.

Female factors account for 50-70% of infertility. These may be overestimated because men are less likely to be examined and because unexplained infertility is often arbitrarily attributed to the feamle.

Female factors include tubal damage, ovulation disorders, and endometriosis. Tubal inflammation, damage, or distortion can result from pelvic inflammatory disease (gonorrhea, chlamydia), postpartum or postabortal infections, endometriosis, and tuberculosis.

Ovulation disorders result from hyperprolactinemia, polycystic ovarian disease, and thyroid, adrenal, and pituitary disorders. They account for at least 20% of female infertility.

Endometriosis, the presence of ectopic endometrium, has long been associated with infertility. It can cause pelvic adhesions, and tubal damage thus impairing the ovum pickup mechanism. Even small amounts of endometriosis not anatomically impairing tubal function are often seen in infertile women.

The success of surgical treatment of infertility depends on the restoration of normal pelvic anatomy and on the initial damage present in the fallopian tube.

Treatment of ovulation disorders is aimed at the causative factor. The administration of bromoergocriptine, clomiphene citrate, human menopausal gonadotropins, or gonadotropin releasing hormone is widely used and successful in achieving ovulation and pregnancy in many women.

Male factor accounts for at least 30% of infertility, and contributes to an additional 20%. There are few successful treatments for male infertility probably becase of our relatively poor understanding of male reproductive functions. Artificial insemination with donor semen is often used as treatment in couples where the husband has azoospermia or severe oligospermia. Active research in this area promises to lead to better understanding of sperm physiology and transport and will undoubtedly result in new and improved therapeutic modalities.

This is an exciting time for those taking care of infertile couples. The new technologies (IVF, GIFT) have and will lead to better diagnostic testing and more directed treatment options making it possible to help the majority of couples achieve a much wanted pregnancy.

Mrs. SCHROEDER. I want to thank all of you. I know you have, in your medical experience, had to deal with insurance companies before, and this triggering word of "experimental".

I know on the Armed Services Committee, as we looked at CHAMPUS programs we dealt with the issue of kidney transplants.

Do any of you know—I realize you are not insurance experts, but do any of you know when or how they define "experimental"? In other words, the success rate that you are having certainly sounds like it is much better than what we had with kidney transplants. It finally reached a magic point where they moved it over the experimental line.

Dr. DECHERNEY. Well, it is easy to know what they call "experimental," that is any new technology that appears on the scene that begins to be used on a routine basis.

The question that I can't answer is what allows them, or what forces them to change something from an experimental procedure to something that becomes a so-called routine procedure. Heart transplants are still experimental, even though they have been done for 15 years, and a fair number of them are done each year.

So, it is difficult to tell what forces them to do it. Their desire is to keep things as experimental procedures as long as possible. So, I don't know what the compelling force is that changes their minds.

Mrs. SCHROEDER. We have certainly found that in the Armed Services Committee. We have never found a uniform definition, to determine a success ratio which would then trigger a procedure over the experimental line and make it a routine treatment.

But you don't know that definition either. Insurance companies just are not inclined to pay. And as long as they can keep it experimental, they will.

Have you had experiences with people using the IVF procedure two and three times, who have become pregnant each time?

Dr. DECHERNEY. You mean repeated cycle?

Mrs. SCHROEDER. Yes.

Dr. DECHERNEY. You mean they get pregnant once and then come back for a second baby?

Mrs. SCHROEDER. And then come back for a second baby, or a third baby?

Dr. DECHERNEY. Yes, this is definitely part of all of our programs that we have had repeats. We don't have more than two children in our program, we don't have anybody with three children, but I don't think that the program has been in existence long enough to have three. Only probably yours, and that would be 6 years. So 3 children in 6 years, that's pretty hectic.

Dr. ALEXANDER. There are couples who have come back, as Alan said, and have had a second child.

Mrs. SCHROEDER. So, while it is a very difficult procedure, and very stressful, people have found it worthwhile doing it again, if it is positive, and have even gone through it again if it has been negative, clearly to make another try at it.

Dr. DECHERNEY. Even failure patients go through two and a half times. So, even those patients that are not successful—I mean, you can understand why somebody who is successful will come back for a second child. I mean, this is a pleasant experience, because the

end point is pleasant. But even patients that fail come back, and in fact, we don't do patients more than four cycles. And many of them would like us to do them more than four cycles, even though they have not been successful.

Dr. BUSTILLO. In our program we do patients more than four cycles. We do have a patient who is presently just about to deliver, who got pregnant on her eighth initiated cycle in vitro.

We have a patient who has done 11 cycles and is ready to do it again. I think part of the reason is because we have simplified it and tried to make it without general anesthesia and it is an outpatient procedures.

But in spite of that, I think the patients undergo a tremendous amount of stress coming in every morning, having their blood drawn, going through all of these repeated testing procedures. But I think that the motivation of these couples is so great, that they will do anything—they tell me if you tell me to stand on my head for half an hour every day, I will do it, if you think it will improve my chances of getting pregnant.

So I think that this doesn't stop them, if they can afford it and they sort of pick themselves up by their boot straps, in terms of their psychological makeup and their relationship, and they continue.

Dr. ALEXANDER. I would like to add one thing there. And that is that I think it is reasonable for insurance companies to put a limit on the number of cycles that they would cover. I am not against a couple coming in 11 times. On the other hand, it would seem that there could be some—say, three cycles that would be reasonable for coverage.

Mrs. SCHROEDER. Well, when you have gone through this process for some—whatever number of cycles, and they have not been successful, is there a way to diagnose why? Or are we still out in a never-never land?

Dr. DECHERNEY. If a patient doesn't fertilize—none of her eggs are fertilized by the sperm, we know, but that is a rare occurrence. So, most of the time we do not know why patients don't conceive.

We don't know why patients that are healthy conceive in any one cycle. People don't conceive every month that don't have a problem. We don't know why you will conceive one month and not another.

Mrs. SCHROEDER. There is an awful lot of experimenting, then.

Dr. DECHERNEY. Trial and error.

Mrs. SCHROEDER. Going back to the definition of the word "experimental", it really is much broader than insurance companies would care to admit.

And I take it from all of your testimony, that you have had to turn people away that can't pay.

Dr. DECHERNEY. We definitely turn people away that can't pay, and we definitely accept a certain number of patients in our program that we underwrite the cost of the procedure. But we have limited resources and can only do so much of that.

Mrs. SCHROEDER. Under an IVF procedure, what percentage of that would be covered, if you had a health plan that only covered diagnosis of infertility?

If you had a health plan that covered diagnosis of infertility and the person was diagnosed and went to IVF, is there any portion of the IVF that would be paid?

Dr. DeCHERNEY. A very small portion, probably the initial interview, the sperm count, and some other basic tests that are done.

Now, you could, I guess, be in collusion and trick the insurance companies and say that things like ultrasounds that are done are part of diagnosis. But to be honest, that wouldn't really be true. The majority of the costs, 75 to 80 percent of the costs are for therapy in an IVF cycle.

Mrs. SCHROEDER. Did you mention how many infertile couples are suitable for IVF, what percentage?

Dr. DeCHERNEY. I can't tell you that, I tried to figure that out this morning. And I just cannot tell you what the magnitude is. I know there are 450,000 women that have tubal disease, and at best, tubal disease is cured in 20 percent by a surgical attempt.

So that leaves about 300,000 or 250,000 women in that category for IVF. And each person, or each couple has to be multiplied by at least two for IVF, because they usually go through it at least twice, if they are not successful the first time.

So the magnitude is quite large, but I can't really—I tried to come up with a figure, because I knew that would be an important figure. But give me a little more time, I will come up with one.

Dr. BUSTILLO. I think we have to add to that that IVF is also applied for other indications. So that tubal disease, for instance, in our program, it is only about 50 percent of our patients.

Dr. DeCHERNEY. It is good for patients with unexplained infertility which makes up 15 percent of the total, and it is good for couples with male factor infertility, which makes up 40 percent. That's why the mathematics is difficult.

Mrs. SCHROEDER. I've often heard that pregnancy can help prevent certain kinds of cancer. Is that true?

Dr. DeCHERNEY. Yes, epidemiologically women that are parents are less likely to have endometrial cancer, and actually they have a slight increase in the incidence of ovarian cancer.

Mrs. SCHROEDER. Do you think that the success rate for IVF will improve over a period of time? I take it there has already been improvement. Do we know why, or is it that we are getting better at it?

Dr. DeCHERNEY. Well, we are better at it, and I think that is why it has improved in the last 5 years. But my own feeling, and I would be interested to hear what the other panelists have to say, is that I think that it has reached kind of a plateau as far as success. I don't think in the next 5 years we will be doing things better as far as the basic procedure is concerned.

So that success rate will be about 20 percent per cycle. There will be a slight increase in the success rate as we get better with cryo-preservation, because we will be able to take embryos from the first cycle and freeze some of those embryos and then place them in the uterus in another cycle.

So, if you add the success rate from cryo-preservation it becomes 10 percent, then we will actually be making the success rate per cycle, or ovum capture, 30 percent. But that is kind of a spurious

increase, that is a trick in numbers really, and it really doesn't indicate that we have done much better with the process.

And I think that we have reached a plateau, and it will take some other major breakthroughs and they usually come slowly in science. The nature is that there is a breakthrough and it gets inculcated into the body of knowledge, people get good at it, but it takes time for another breakthrough to occur.

Dr. ALEXANDER. If a couple has intercourse right in mid-cycle and if nothing is wrong, they have a 20 percent chance of conceiving in one given month. And so it is unreasonable to think that IVF can be much, much more successful than that. And, therefore, I think that IVF success has increased by all the things that we have learned, and has become quite successful, and we can not expect much additional increase.

Dr. BUSTILLO. I agree with that.

Mrs. SCHROEDER. Some have said that it might be reasonable to limit the number of IVF tries. Now, you mentioned cycles, but tries would be different right?

Dr. DECHERNEY. Well, the difference is whether you get an egg, or not. If the patient does not have an egg captured, then she has no chance to get pregnant. So that really shouldn't count against the patient. I mean, it's a fine detail.

So, it really should be based on the ability to get an egg. If the patient is given medication and doesn't respond well, that shouldn't count against her, if you set the limit at four. It should really be four successful ovum captures.

Mrs. SCHROEDER. Would you two agree that four successful ovum captures would be a reasonable number?

Dr. ALEXANDER. Well, I would be in favor of four, but I would be willing to negotiate to three, and say that a good percentage of couples conceive after three cycles in which eggs have been produced and fertilization attempted.

Mrs. SCHROEDER. And you would agree?

Dr. BUSTILLO. I would agree, but then you should talk about capture or transfer of embryos, because I think sometimes we utilize IVF when there is a questionable male factor problem, we almost utilize IVF as the final diagnostic technique. Then the woman also has a problem, you then discover the husband's sperm is unable to fertilize, and then she wants to continue doing IVF, should you count that, when she didn't get an embryo?

So it becomes very confusing. And I think one of the confusions, also, is how people report successes—is it by start, or is it by the end point, which is actually the embryo transfer?

So it is very difficult. I think patients should be allowed at least four embryo transfers, and it may take eight initiated cycles to get to that point.

Mrs. SCHROEDER. So you would say not only egg, but fertilized egg?

Dr. BUSTILLO. Yes.

Mrs. SCHROEDER. OK, anybody else?

[No response.]

Mrs. SCHROEDER. Well, I thank this panel very much. You have been most helpful and we appreciate all of your work and every-

thing that you are doing. Thank you for taking time out of your very busy schedules to be here.

Thank you.

Our last panel this morning is Jane Edwards, who is the director, Spence-Chapin Services in New York; Mary Durr, who is the director of Adoption Services Information/ASIA of Washington, DC; and Linda Brownlee, who is a clinical social worker in Alexandria, VA

We are very honored to have you here this morning, and thank you for taking time out of your busy schedules to come help us with this legislation.

Ms. Edwards, would you like to begin?

Ms. EDWARDS. All right.

STATEMENT OF JANE EDWARDS, DIRECTOR, SPENCE-CHAPIN SERVICES, NEW YORK, NY

Ms. EDWARDS. Good morning.

Mrs. SCHROEDER. Good morning.

Ms. EDWARDS. Thank you very much for inviting me to speak before the panel.

My name is Jane Edwards, and I am the executive director of Spence-Chapin Services to Families and Children, which is an adoption and family service, not for profit agency in New York City, serving families and children for adoption all over the United States and children from other countries as well.

We are also members of the National Committee for Adoption. And I thank you and the members of the subcommittee for your leadership and support that you have demonstrated in health and social services causes.

The insurance funding which you are recommending for the federal employees in H.R. 2852 will help people who seem unable to bear children and are longing to be parents, to afford the medical procedures necessary for them to build families biologically.

Most people will go to any lengths, exhausting every medical possibility, if they could afford to do so, before then turning to adoption. H.R. 2852 will help them, also, to build families by adopting children.

So, in many ways by helping families to adopt, we will be helping children who wait for families, while helping the Government and the taxpayers as well.

There are millions of women in the United States who are unable to bear children and for whom medical science offers some hope. Many of them are dealing with the reality and accepting their fate, while others are trying new avenues, some illegal and some questionably legal, including surrogate parenthood.

The point is people who want to build families will find a way. Unfortunately, they will have to pay a substantial price for the medical procedures and a substantial fee for the adoption service, to an attorney, or to a voluntary licensed adoption agency. The average fee across the United States is $10,000. At Spence-Chapin we use a sliding scale, based on income and our lowest fee is $6,000.

We are aware of the difficulty many families have in raising the fee, the money to pay the fee and we help them as much as possible by lowering it, or even waiving it where there is a considerable

hardship, because the fee doesn't pay all of the costs for our agency. More than half is paid for by the agency fund from fundraising events, contributions, foundation grants and the United Way.

Some adoptive couples are fortunate in that one or both enjoy the benefit of their employer's paying the whole fee, or part of it. For most, in the lower income categories, as you spoke to before, Mrs. Schroeder, families earning from $20,000–$30,000 find it next to impossible to pay the fee, what with paying high rents, trying to buy a house, or a car. And those in the higher income brackets think the fee is quite reasonable, if not somewhat low.

We have no problem finding adoptive parents for Caucasian infants. The families wait for children, but it is unfair that only the people with higher incomes can afford to build families without a tremendous hardship.

As for the children of minority backgrounds, and children with physical or emotional problems, the disparity of numbers is the reverse. These children wait for adoptive homes. And these children are American children, not children brought into this country from other countries.

To give Black birth parents even greater choice in selecting adoptive parents for their children, to find adoptive parents for their children, we have reached out to try to find Black couples among 18 New York corporations that offer adoption benefits to their employees. We expanded our paid advertising to additional ethnic newspapers and to the competitive Yellow Pages market, and we advertise in Black magazines across the country. We also advertise in The Chief, a newspaper for Federal employees.

And the results of our advertising strategies have been encouraging, increasing the number of families interested in adopting infants of minority backgrounds. Still more families are needed for these infants who wait. And this is sad, because the program enables young women with unintended pregnancies to consider the adoption alternative, and if they prefer adoption, they can go on with their lives without going on public assistance. Their infants are then adopted without going through the public system, and at no cost to the Government and the taxpayers.

And as long as we have adoptive parents, the infants do not have to go into Government-supported foster care and are placed in adoptive homes without Government subsidies.

However, most black families find it difficult to pay a fee. Many of these families are responding to our appeal, to make room for a waiting child, and feel that they have already biological children and cannot afford a service fee, and we shouldn't even expect them to pay one. And while we have no problem with fees being paid by a white affluent family, our deficit in the minority adoption program is over $500,000; half of which would have been covered by fees, if the adoptive parents could have afforded to pay them.

But the Government-supported foster care and adoption system is not the answer, because bureaucratic regulations prevent an early resolution of the birth parents plans and children remain in foster care inordinately long, until often they are too old to be easily adopted. Not to mention them having problems, other than

age, which result from the revolving door living arrangements and inadequate parenting.

We, in the voluntary agency sector feel that we could expand the services to birth parents and infants, and help people to build families, if we could afford to do so. The fees for service are necessary for our continued program operation. If the fees were reimbursed to federal employees, or paid by insurance, this would serve to encourage adoption by those employees and the programs would be an incentive for private corporations and industrial organizations to emulate.

In conclusion, the Federal Employee Family Building Act would help people by providing insurance to cover the medical expenses of building families biologically, and would be a way for the Federal employees to build families by adoption, and simultaneously meet a social need of children waiting for families, preventing the need for foster care and the expenditure of millions of Government funds for foster care and adoption subsidies.

Also, couples and single people of lower income could build families equitably, along with the more affluent.

Again, I want to thank you, Mrs. Schroeder, for all of your efforts on behalf of these families and children, and for the opportunity to appear before you this morning to present my views.

[The statement of Ms. Edwards follows:]

STATEMENT OF JANE EDWARDS, EXECUTIVE DIRECTOR, SPENCE-CHAPIN SERVICES TO FAMILIES AND CHILDREN, NEW YORK, NEW YORK

My name is Jane Edwards and I am the Executive Director of Spence-Chapin Services to Families and Children in New York City, which is an adoption agency, and my experience in adoption is over 25 years.

I am a member of the Child Welfare League of America and the National Committee For Adoption, and I am on the Board of Directors of the Harlem-Dowling Children's Service, a minority managed adoption and foster care program in Central Harlem in New York City.

There are several reasons related to adoption why the Federal Employees Family Building Act should pass into law.

There are thousands, probably millions of women in the United States who are unable to bear children and for whom medical science offers no hope. Many of them are dealing with the reality and accepting there fate while others are trying many new avenues, some illegal others questionable, including surrogate parenthood. People who want to build families will try to find a way. Unfortunately, they will have to pay a substantial fee for the adoption service, to an attorney or to a voluntary licensed adoption agency. The average fee across the United States is $10,000. At Spence-Chapin we use a sliding scale based on income and our lowest fee is $6,000. We are aware of the difficulty many families have in raising the money to pay the fee, and we help them as much as possible by lowering it, even waiving it where there is considerable hardship. The fee does not pay all the

costs to our agency. More than half is paid by agency funds from fund raising events, contributions, foundation grants and the United Way. Some adoptive couples are fortunate in that one or both enjoy the benefit of their employers paying the whole fee or a part of it. For most in the lower income categories, particularly the young couples whom the birth parents prefer to adopt their children, earning in the $20,000 to $31,200 bracket, find it next to impossible to pay the fee what with paying high rents, needing an automobile, etc. Those in the higher income brackets think the fee is quite reasonable, if not somewhat low. We have no problem finding adoptive parents for Caucasian infants. The families wait for children but it is unfair that only the families with higher incomes can afford to build families without a tremendous hardship.

As for children of minority background, children with physical or emotional problems and older children, the disparity of numbers is reverse. These children wait for adoptive homes.

The need for foster care and subsequent adoption for black children which was tremendous during the '60s, has returned. We are finding the admissions to foster care suddenly increasing now after many years of children rapidly leaving care. Housing and employment problems in the poor black community and drug dependency of youth is now in crisis proportions. Teenage pregnancy throughout the USA is an epidemic with most of these birth parents keeping their infants, continuing the cycle of poverty which is a great cost to them and to our government.

Operating on the supposition that most unwed mothers were completely unaware of the adoption option as a desirable alternative to early parenting, two years ago we set out to inform and educate youth with unintended pregnancies so they could make informed decisions.

The strategies used by the Spence-Chapin Adoption Option Program produced a 30-35% increase in birth parent clients overall, a 25% increase in white birth parents and a 64% increase in black birth parent clients seen and 63% more black and white infants surrendered for adoption. Our activities included Public Service announcements, radio and T.V. interviews, paid advertising in ethnic newspapers and Yellow Pages and the distribution of a new brochure. We have established working liaisons with schools, hospitals and maternity shelters, and we have initiated group counseling services for parents before and after surrender.

To give black birth parents even greater choice in selecting homes for their babies, and simultaneously help couples to build families, we tried to recruit adoptive parents among 18 New York corporations that offer adoption benefits to their employees.

We expanded our paid advertising to additional ethnic newspapers and to the competitive Yellow Pages market. We advertised for black adoptive homes in black magazines with national publication and we advertised for black adoptive parents in The Chief, a newspaper for Federal employees.

The results of our advertising strategies have been excellent, increasing greatly the number of families interested in adopting infants of minority background.

This program enables young women with unintended pregnancies to consider the adoption alternative and if they prefer adoption, they can go on with their lives without going on public assistance. Their infants are then adopted without going through the public system and at no cost to the government and to taxpayers.

As long as we have adoptive parents, the infants do not go into government supported foster care and they are placed in adoptive homes without government subsidies.

Since July 1, 1986, we have placed 39 black infants and 38 white infants in adoptive homes without government subsidy.

However, this program is very costly to our agency. It costs the agency $14,000 to place an infant in an adoptive home. This includes approximately $11,000 in birth parent and child related costs for medical care, maternity residence and boarding care for the child, and $3,000 for adoption related costs, recruitment, Home Study and supervision costs.

Although we are a fee charging agency (fees are paid on a sliding scale) and adoptive parents are asked to pay service fees, most black families find it difficult to pay a fee. Many of these families are responding to our appeal to make room for a waiting child and feel that they already have biological children, cannot afford a service fee and that we should not expect them to pay a fee. While we have no problem in fees being paid by white families, our deficit in the minority adoption program is approximately $550,000, half of which would have been covered by fees if the adopting parents could have afforded to pay them. Only $39,000 was collected in fees from parents adopting children of minority background, an average of $1,000 per child.

The government supported foster care and adoption system is not the answer because bureaucratic regulations prevent an early resolution of the birth parents' plans and children remain in foster care inordinately long - until often they are too old to be easily adopted, not to mention their having problems other than age which result from revolving door living arrangements and inadequate parenting.

We in the voluntary agency sector feel that we could expand these services to birth parents and infants and help people to build families if we could afford to do so. The fees for service are necessary for our continued program operation.

If the fees were reimbursed to Federal employees, this would serve to encourage adoption by those employees and the program would be an incentive for large private corporations and industrial organizations to emulate.

In conclusion, the Federal Employee Family Building Act would be an equitable way for Americans to build families and simultaneously meet a social need of children waiting for families, preventing the need for foster care and the expenditure of millions of government funds for foster care and adoption subsidies. Also, couples and single people of lower income could build families equitably with the more affluent.

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Mrs. SCHROEDER. Thank you very much, we really appreciate that.

Ms. Durr.

STATEMENT OF MARY DURR, DIRECTOR, ADOPTION SERVICE INFORMATION AGENCY SERVICES/ASIA, WASHINGTON, DC

Ms. DURR. It is my privilege to be here today and to share with you the reasons for my support of the Federal Family Building Act of 1987.

There comes a time in the lives of most people where they want to be parents, to raise the next generation. Most of us are able to become parents at will, but for a significant number of couples this is not so. Due to a variety of reasons, they cannot conceive a child to fulfill their need to nurture.

As pregnancy eludes them, most turn to the medical profession for help in diagnosing and remedying that situation. This takes time. One consultation after another, tests, procedures, and medication follow, always with the hope of producing the desired pregnancy. Some couples find rather quickly that their chances for conception are minimal, and they begin to deal with that fact, others continue, relying on medical technology with the hope for future success.

Those who are good candidates for artificial insemination or in vitro fertilization have to decide whether to pursue these possibilities, which may have to be repeated multiple times. One factor in the decision must be the cost of these procedures, which often are not covered by medical insurance. Those who become pregnant through this technology feel the result is well worth the cost.

The pursuit of a biological child through this means is an expensive, long, emotionally and physically draining process. At various junctions, some couples change course and turn to adoption.

Also turning to adoption are those couples who for genetic reasons choose not to have a child, fearful of inflicting a dreadful disease on an innocent child. Some couples choose to raise a child who is already born, rather than bringing another being into the world. The adoption process, at its best, includes examination of the couple's readiness and ability to parent an adoptive child. This is also the time for professionals to work with the couple in assisting them with any unresolved feelings and ambivalances that they may have.

During this process, agencies are responsible for educating families about the differences between biological and adoptive family building—these are children with different genes, often from another culture or race.

Couples who are candidates for adoption do not all have equal access to it. The cost of adoption is a hardship and a deterrent. Public social services do not charge fees, but they have few infants for placement and waiting periods of several years. Couples who are able to adopt through private agencies which have access to infants have briefer waiting periods. They save or borrow to cover the fees which run thousands of dollars.

Our agency encourages each couple to save ahead and cover the cost of adoption before placement, in order to make easier the fi-

nancial responsibilities inherent in building a family. There are qualified perspective parents for whom this financial commitment is impossible.

The desire to procreate and raise the next generation should be a choice. The Federal Employee Family Building Act would open possibilities for some to bear children, and others to create families through adoption. This act would take its equitable place, joining medical insurance, disability insurance, social security insurance, SSI and others.

Thank you.

Mrs. SCHROEDER. Thank you very, very much.

Ms. Brownlee.

STATEMENT OF LINDA BROWNLEE, CLINICAL SOCIAL WORKER, ALEXANDRIA, VA

Ms. BROWNLEE. Thank you for letting me come and speak to you today. I am coming here not only as a clinical social worker in private practice, but as an infertile woman, as the mother of two adopted children, who are five and eight years old. And, also, because I wanted to have an opportunity to do something which I consider real and tangible for the infertile clients that I work with, clients who come to me, to receive some help with their infertility, and the psychological pain with which they are dealing.

Let me tell you a little bit about what infertile couples go through. They work very hard, they go to some of the doctors that you heard speaking earlier. Hopefully, they will also seek psychological counseling, which is a very big part of the help they will need. No one can be expected to get through this process without a great deal of support.

The issue of infertility is never very far away from their minds. They are almost obsessed with it. They have several monthly appointments. If they are in an IVF treatment that particular month, they are spending 5–10 mornings of their cycle at the clinic, or wondering whether or not they are pregnant after the medical treatment is completed.

These couples proceed through five stages, which are very similar to what you go through during the stages of death and dying. The first one is a state of denial, you can't believe that this could possibly be happening to you. You thought that you were going to grow up, get a job, marry, and have children whenever you chose. It was the whole picture that you felt you were entitled to have.

But slowly it starts to dawn on you as the months pass that conception is not occurring. When you start to realize that something is wrong, you begin to bargain. I remember my bargain with God, as a good Catholic girl, that if God gave me a son, I would certainly give him back a priest. I don't know if He wants my son, Matthew, but He can have him. Matthew has a wonderful sense of humor and a loving way, and we are thrilled to have him and his sister, Lauren, in our family.

You can see that even as I speak about this, I become emotional. It was emotional for me to just see the families and children in this room today, because it brings back what it was like for me to experience infertility.

After the bargaining, comes feelings of anger. Why is this happening to me? Why was I chosen? Anger is frequently directed towards the doctors, the doctors who don't seem to be helping you to get what it is that you would really like to have, a baby. Anger is easily noticed—you have short tempers, you are angry at every one, and marital distress surfaces

Loss, I think, is one of the hardest stages for a couple to feel. You feel the loss in the empty arms that you have, the wish to see the child that you never had. The most frequent comment I get is that it seems like everyone in the supermarket is pregnant. Every time you see a person who has a child, or even a diaper commercial on television, you feel sad and you feel anger, because you don't have a baby.

Working through this process though, there is a happy ending to all of this, whether you choose to have a child-free life, choose to adopt, or are fortunate enough to have a biological child. You are able to love, work, laugh and play again, which I think is real important, and your life is much brighter. But you don't get there all by yourself. You need medical intervention which is expensive, you need intervention by adoption agencies, and psychological counseling.

Since the time, I was working through my infertility issues, the state-of-the-art has certainly improved. Now it costs a great deal to go through an IVF procedure, $5,000 to $6,000 a cycle. When a couple is trying to get the money together to be able to do this expensive procedure, they are really chipping away at whatever savings they might have, whatever money they would have with which to begin a family.

Last month a woman came to see me, a very attractive 28-year old woman, who had just had a laparoscopy and discovered as a result of that process, that her tubes were blocked. Her husband is a military pilot the only insurance they have is CHAMPUS. This woman came in, knowing that she was prevented from concieving a baby without IVF. They did not have the money to pay for an IVF procedure. Their insurance wasn't going to pay for it and they did not have the money themselves. She had to begin the process of giving up her dream child, the child that she and her husband would have had. It is painful for her, it is painful for all the people who are affected—there are grandparents who are not going to be grandparents, and there are cousins who are not going to have another cousin with whom to play.

I think this system is inequitable. There are people for whom infertility treatment is only possible because they have the money to pay for it and that really is not fair. Infertility doesn't affect only those who can afford it, it affects 1 out of 6 couples regardless of income.

Thank you for the opportunity to express my views. I certainly am in favor of the Family Building Act. Thank you.

[The statement of Ms. Brownlee follows:]

Testimony of Linda R. Brownlee, L.C.S.W., in support of H.R. 2852, The Federal Employees Family Building Act before the Subcommittee on Civil Service.

I want to thank the subcommittee for the opportunity to testify in support of the Federal Employees Family Building Act.

I am a wife of a federal employee, the mother of two adopted children, and a clinical social worker in private practice working with couples who are experiencing infertility problems. My testimony reflects my own personal experiences as well as the experiences of other infertile couples in their struggle to build a family.

Infertility, as defined by the American Fertility Society, is when a successful pregnancy leading to a live birth has not occurred within a year of regular sexual relations without contraception. This definition includes miscarriages and stillbirths which are not often thought of as an infertility issue. In the U.S., this means approximately one out of six couples is having difficulty conceiving or carrying a pregnancy to term.[1] During the first year of trying to conceive, 80 percent of all sexually active couples will conceive; 15 percent in the second year; and a smaller group in the third year. The

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[1]Menning, B.E., Infertility: a guide for the childless couple. New Jersey: Prentice-Hall, 1977.

remainder, approximately nine percent, will have a decreasing ability to conceive without medical intervention.[2]

Many factors account for infertility. Among them are ovulatory problems, endometriosis, delayed childbearing for educational, financial, or career reasons, pelvic inflammations, responses to various drugs (DES, radiation, environmental pollution, chemicals), and venereal disease. Causative factors for infertility reside 40 percent female factors, 40 percent male factors, ten percent combined male and female causes, and ten percent unexplained infertility.

Infertile couples are your neighbors, your grown children, your fellow employees who suffer internally with the invisible stigma of infertility. Outwardly, there is no scar, they appear whole, capable, and in control. Inwardly they are on an emotional roller coaster. Every month the painful cycle of highs and lows parallels the menstrual cycle. Will this be the month I finally conceive? The month is filled with medical appointments for tests, injections, ovulation stimulation, inseminations, sex on schedule and then watching, waiting for the daily temperature chart to continue with an elevated temperature indicating pregnancy has occurred. When menses occurs, the whole body mourns the loss of the baby that wasn't conceived. You feel like the bottom has dropped out of your life; you feel empty and defective, and out of control.

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[2]Mazor, Miriam D., M.D., and Harriet F. Simons. Infertility: Medical, Emotional and Social Considerations. New York, N.Y.: Human Sciences Press, Inc., 1984.

Many couples, overwhelmed with helplessness, anger and loss, are unable to learn from other infertile couples that what they are going through is nearly universal. Denial, bargaining, anger and a sense of loss -- four of the emotional stages of infertility -- too often prevent the sharing and mutual expression of these predictable feelings. Often the wife goes through the stages of infertility more openly than when compared to her husband. He may be supportive, and want to "fix" his wife, but he distances himself from the painful emotions involved. Marital distress followed by questioning whether or not to continue the marriage in the face of this crisis exacerbates the situation.

As the months of trying to conceive pass, the annoying doubt that maybe you can't have a baby begins to surface. The first stage of infertility's psychological process is denial. For some couples, denial is shattered by a blunt discovery: no sperm are present or fallopian tubes are blocked making pregnancy impossible without expensive and intensive medical intervention. It seems impossible to absorb such painful information. Tests are repeated, but the conclusion remains the same. For others, months of trying to conceive turn into years of seeking more and more information, another doctor or a new technique, all in hopes of regaining control of your reproductive functioning.

From denial, you move on to bargaining, usually with God, or sometimes with yourself. You promise to be good forever if only you can be rewarded with a child. With each new treatment, you offer up another bargain, any bargain to guarantee success. "Give me a son, God, and I will give you back a priest," was one of my

bargains. An examination of your life is undertaken, reviewing anything that you may have done that would have caused the infertility. This is especially guilt-producing for couples who have had abortions in the past, or used contraception that might have caused the infertility.

When the bargaining doesn't work, anger, the third stage of infertility, begins to set in. You are angry at your situation, at fate in general. It seems so terribly unfair. Why me? It is never taken for granted that anything will work out again. Frequently, anger is directed at the doctor, who may have been insensitive. Some doctors callously tell very painful information over the phone, rather than scheduling an office visit. Having an enlightened social worker or a nurse who is trained in the psychological process available in the doctor's office can be of tremendous assistance to both the doctor and the couple at such difficult times. Counseling individually or in a group can decrease the isolation and provide a supportive network for the couple while working through the medical work-up and making the choices involved.

It seems that every woman in the supermarket is pregnant. The infertile couple finds themselves avoiding friends with babies and staying away from baby showers and family celebrations involving children. Attending these events is simply too painful a reminder of your not having a child. The isolation is protective in nature. Telling family members of your infertility means that you are also telling them that they will not have a biological grandchild, a cousin, a niece or nephew. It means

sharing sexual information with others who do not always know how to provide the support you need, often giving you pat responses such as "relax, you'll get pregnant," which is not helpful. Or "adopt and you'll get pregnant," which statistically only occurs five percent of the time.

During the anger stage, interest in sex may diminish. Making love and having sex to conceive a baby are not the same. Some couples withdraw from each other, needing to repair their hurt by themselves. Short tempers, tension, stress and avoidance of intimacy are the side effects of anger and isolation. Anger is sometimes felt towards the person who is infertile. The male partner expresses this sometimes non-verbally through temporary impotence.

Compensating for feelings of inadequacy and loss of self-esteem, some throw themselves into their work, accepting a greater workload and seeking a frantic pace of ever-increasing obligations. A sense of humor, which helps to get through tough times, disappears.

Anger and isolation are followed by the stage of loss. It is the loss of the biological child who has your blonde hair and your husband's crooked little finger. I remember feeling empty arms imagining what my child would have looked like. I'll never know for certain what he or she would have been like and it still makes me sad never to have seen the child we would have had together. There is no funeral for our dream child, no sympathy card, no outward marking of the emptiness we feel.

The fifth and final stage of infertility is resolution, which comes from accepting the feelings and integrating them into your sense of self. Resolution brings renewed energy to love, work, and play. A sense of humor returns. You can walk away from your infertility, having learned essential tools for living. The infertile couple is then free to build their family as adoptive parents or choose a child-free life style.

Against this backdrop of psychological pain is the aggravation of how much of the medical expenses the insurance company will pay. Money magazine reports that insurance companies may not regard infertility as a disease and will not pay for treatment because it is considered experimental. The way the doctor words the bill to the insurance company determines whether payment will be made.[3]

Let me illustrate how the money issues affected a couple who are both employed by the federal government in a professional capacity. In 1986, the husband needed microsurgery in another city to improve his sperm count. The surgeon demanded his fee of $10,000 one month in advance of the surgery. The couple paid this fee in advance, not knowing whether or not Blue Cross and Blue Shield would reimburse them. They filed for compensation immediately after the surgery and six months later the couple was reimbursed by Blue Cross and Blue Shield for 80 percent, of $6,000 which Blue Cross and Blue Shield considered to be the usual and

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[3]Harris, Diane, "What It Costs to Fight Infertility." Money Magazine, 201-212, December 1984.

customary fee for this surgery. In 1986, this couple's income tax return reported $15,000 of unreimbursed medical expenses.

Last month, an attractive 28-year-old woman came to see me for psychological counseling for infertility after she learned that her tubes were blocked, making pregnancy possible only through in vitro fertilization (IVF). Her husband is a career military officer and the IVF treatment option is not available to her because her insurance considers IVF to be experimental. She is saddened by the loss of the child that she cannot have and angry at the inequity of the system that allows the privilege of IVF treatment for some, but not for her because of the lack of reimbursement by her insurance company.

Many couples who have sought medical treatment for infertility, reach the point when they have to let financial considerations determine whether or not they will continue treatment or seek adoption. Adoption fees can run up to $10,000, which is equal to two IVF procedures. They have to make a choice between the two options knowing they can only choose one. Stopping short of trying every option, leaves many couples feeling guilty and unresolved. If only we would have tried this procedure, they ask themselves, maybe we would have had a child. Resolution of the infertility issue makes the bonding to an adopted child more likely to occur. This is preventive family therapy and helps to build a stronger family.

The stress and psychological pain are real. Infertility, though frequently invisible is real. The financial barrier to

medical treatment of infertility is real. High adoption costs are real.

When couples are fortunate enough to conceive a child through medical intervention, they often begin their family with less money in the bank due to the costs of treatment. Many adoptive families are aware of the debt caused by the adoption fees. Although they are grateful for the child, they are beginning their dream of a family with a financial deficit.

I support the Federal Employees Family Building Act which would require health insurance plans to provide coverage for fertility treatments and adoption.

Thank you very much for this opportunity to present my views.

Mrs. SCHROEDER. Thank you all very much.

I wanted to ask whether it costs as much to adopt an older child that has been in foster care?

Ms. EDWARDS. No, it doesn't because that child would be in the public system, and the government would pay the fee for that child.

Mrs. SCHROEDER. So that is less expensive. And of course one of the tragedies is how little families receive for providing foster care, at least in my area. We are having great trouble finding foster care parents and a lot of them then want to adopt, and there are problems with that, too. But kennel fees in my area are higher than what we pay for foster care, and that really tells you something about priorities.

As we talk about minority and lower income families, statistics show that they have a higher incidence of infertility, and yet they haven't shown up as much for adoption. Do you think it is because they think they can't afford it?

Ms. EDWARDS. I disagree with you that they haven't shown up for adoption. I think that in the categories of people who usually come to adopt, black families do show up in large numbers. And I think that maybe even a higher percentage than white families. There also is a cultural pattern of quasi-adopting relatives children and neighbors' children who have special needs. But I think they do show up, they have a tremendous problem paying the fee, they absolutely cannot afford it.

And when they do, it is at a great hardship to them.

Mrs. SCHROEDER. Has anybody got statistics on how many couples you must turn away in a year, because they can't afford the fee?

Ms. EDWARDS. We do not turn them away, but many drop out on their own, because of the fees.

Ms. DURR. We don't turn away, but we tell them the fee—they sort of self-select. So we don't know exactly the number, but here and there they tell us "We can't afford that".

Also, I know that the families that do come, some of them—you know, a coal miner from West Virginia, a maintenance man from south Virginia—it is very, very hard.

Now, once they have the child, you know, it is worth everything and they are happy to have the child, but the cost is just one of the things.

Mrs. SCHROEDER. Do you require, Ms. Durr, that couples have a certain amount of savings to qualify?

Ms. DURR. No, they don't have to have that.

Mrs. SCHROEDER. So, I take it that what everyone is saying is insurance coverage would help, that at least it would pay some of those costs. And you would be able to be much fairer, it wouldn't be money selecting people out.

Ms. EDWARDS. Well, you can tell the difference right away, when a family knows that their fee coverage is going to be paid by the employer, because they are much more eager and much more hopeful. And the others are quite worried about how they are going to get it together.

Mrs. SCHROEDER. So, you think it would really expedite the whole process?

Ms. EDWARDS. Yes.

Mrs. SCHROEDER. Thank you all very much for being here, I really appreciate your shedding light from your perspective on this issue.

And with that, we have ended the first day of hearings on this bill. We thank you all for your participation and insight.

And if there is anything people think we have overlooked, we would be more than happy to have it submitted for the record. And we will put all the witnesses' full testimony in the record.

With that, the hearing is adjourned.

[Whereupon, at 11:30 a.m., the hearing was adjourned.]

[The following information was submitted for the record:]

National Committee For Adoption
Suite 512/2025 M Street, N.W./Washington, D.C. 20036/202-463-7559

August 18, 1987

The Honorable Patricia Schroeder
U.S. House of Representatives
Washington, D.C. 20515

Dear Representative Schroeder:

On behalf of the membership and Board of Directors of the National Committee For Adoption, I am writing in regards to H.R. 2852, the "Federal Employees Family Building Act of 1987." Once again, we wish to thank you for providing leadership in addressing the barriers to adoption. Certainly, the necessary costs of adoption provide an obstacle to many families who wish to provide a home to a child through adoption.

The National Committee For Adoption, with more voluntary sector adoption agencies in membership than any other national, non-sectarian organization, fully endorses the provisions of H.R. 2852 that would reimburse Federal employees for adoption expenses. We are unable to fully endorse the entire Act, however, not because of any opposition to infertility treatment but rather because the issue of financing of such treatments is outside our expertise and purview.

We look forward to working with you to see the adoption provisions of H.R. 2852 enacted into law and thank you again for being such a strong supporter of adoption as a means of family building.

Sincerely,

Bill Pierce

William L. Pierce, Ph.D.

Director, Reproductive Endocrinology
Department of Obstetrics and Gynecology
Yale University School of Medicine, New Haven, Connecticut

Major technological breakthroughs have occurred in our own precisely defined area of specialization; and we can only be overjoyed and exhilarated and consider ourselves extremely fortunate to be working during a period of time when such paramount advances have been made. How thrilling it must have been to be Chaucer writing when Gutenberg invented the printing press, or be a physicist working on the Manhattan Project!

Very few have this opportunity to be present at the nascence of profound new ideas and applications so intimately related to one's own field.

Clearly, this advance, like children, offers not only great joy but also a tremendous amount of responsibility. This is always the case when knowledge has outdistanced wisdom. The editorial by Jones[1] in this journal 1 year ago explored basic ethical, religious, and moral issues associated with this new technology. Now we have to come to grips with the more mundane and pragmatic issues associated with IVF.

Two of the main subjects to be addressed are craftsmanship and commercialism.

On craftsmanship: our primary goal must be that we remain physicians, members of a learned profession; we must not fall into the dual trap of becoming technicians or merchants. In IVF, it can be alluring to divide work into comprehensible units, so that ultimately no one understands all of them. Such specialization would be a giant error, because specialization should increase one's depth instead of making one more narrow.[2] Individual growth (keeping up) is essential. As Eddie Arcaro, the famous jockey, once said, "Once a guy starts wearing silk pajamas, it's hard to get up early."[3] The problem is that we have never been so dependent on nonphysi-

Received October 19, 1983.
Reprint requests: Alan H. DeCherney, M.D., Director, Reproductive Endocrinology, Department of Obstetrics and Gynecology, Yale University School of Medicine, 333 Cedar Street, New Haven, Connecticut 06510.

cians—that is, the reproductive physiologist—for success. To become a superb inducer of ovulation or an expert laparoscopist or excellent at embryo transfer is not enough. We must maintain excellence in understanding all aspects of this craft if we are not to become mere technicians. For should that come about, the next step is likely to be commercial control of our endeavors.

On commercialism: how this new technology will be distributed to the public is a second timely issue. Hoechst Pharmaceutical has given a $70 million gift to the Massachusetts General Hospital for studies in molecular biology. Yale now requires annual disclosure of consultative arrangements, as well as substantial investment holdings, etc.[4] The engagement of industry and academic medicine has been announced, with marriage planned soon. What better area could there be to test out commercialized medical crafts than the area of IVF. This field is potentially highly profitable, limited in scope, and based on high technology.

It seems to me that there are at least three pathways the commercial aspect of IVF might take in the future. They are (1) the continuance of strictly academic centers, (2) individual privately owned IVF clinics dictated by geography, and (3) an IVF industry. Only the third idea is controversial and control provide the human element of the practice of medicine by yielding to pristine white centers managed by administrator-businessmen and white-frocked *technodocs*, we might lose much of what we consider important in medicine. Should we use our newfound knowledge to create centers where babies can be officially manufactured, with children becoming a commodity, as suggested in the *Time* magazine essay "The Baby Factory"[6]: "Technological parenthood may have the trapping of business, but it is not big business; it is the answer to someone's most personal prayers."

The less theatrical alternatives have inherent problems as well. Many private sector clinics are needed worldwide. How many cases should they handle per unit to be efficient? What is the market? Wouldn't they suffer from lack of quality control? Isn't there a potential for tremendous exploitation? On the other hand, the university hospital and academia have tended not to be very supportive of this endeavor either. Perhaps they lack the resources. An article by our group similar to the one published in this issue of *Fertility and Sterility*[7] was rejected by a prestigious journal catering to broader interests. It was rejected for a number of reasons, but the most cogent one was that the editors questioned the usefulness of

sial and yet creative, threatening to catapult the obstetric-gynecologic community into Relman's medical industrial complex.[8]

Health maintenance organizations and 1100 proprietary hospitals are already well established on the medical scene. Dialysis has become an industry. Professionally planned IVF centers, managed and marketed, seem a likely extension of this concept. Ten years ago this route of medical care seemed odious and unethical, but today it might represent what the future holds for all of medical science: a technocracy. With rapid and extreme technological advance comes a desire for regulation. Wouldn't industry and business be best at this? The National Institutes of Health and federal government, by failing to reconstitute its ethics committee as it was directed to do by its own staff, has opted out of leadership. The insurance industry as well has relinquished responsibility by refusing to pay for these procedures. Yet regulating ourselves could backfire, in that the march of progress might be slowed and innovation stymied as the regulators are made less productive by having to perform administrative functions. And so we have a paradox: since regu-

a situation where 9 full-time employees devoted their time to 66 patients. They suggested it might be more important for Yale to do *research only* with regard to IVF, rather than trying to provide a service, too!

Therefore, if proficiency and efficiency are the major concerns, the marketplace may be a desirable setting in which to provide in vitro services for patients. Since technology has made viable all of the alternatives discussed, it then becomes a question of the medical profession properly allocating health resources in these times of economic responsibility. If anyone doubts that this new technology represents a new way of thinking about the practice of medicine, one only has to remember that the UCLA-Harbor Group has applied for a patent for their in vivo process. I wonder whether trenchant evaluation of the market for in vitro services will cause us to determine the proper commercial course.

Everett Dirksen said, on nominating Barry Goldwater as a presidential candidate, "There is nothing so powerful as an idea whose time has come."[3] This is evidenced by the five articles on IVF in this issue of *Fertility and Sterility*.[7-11]

They cover all aspects of the procedure, including polyspermia, ovulation induction, and predictability and determination of success rates. Most of the specific technical advances, past and future, were considered, in an unrandomized way, in Ed Wallach's editorial in this journal a year ago.[12] Some components require further inquisition, though, including cryobiology, the possible abolition of tubal surgery, sex selection, the orphan embryo, ovum capture utilizing ultrasound only, genetic engineering, and the possibility that every patient undergoing a laparoscopy for any fertility-related problem should also have a concomitant shot at IVF. Also, we must not lose sight of important advances that might not relate directly to IVF but are spin-offs: for instance, our improved methods of processing sperm for intrauterine insemination and heightened inquisitiveness into ovulation induction, as well as our understanding of follicular metabolism, which has already grown at a rate that has rapidly outstripped our ability to integrate this material. It's a little like man getting to the moon. Yes, it was wonderful that man could walk on the moon; it was a dream of mankind's come true. But many of the important technical advances were spin-offs from the main achievement—computer growth and the development of distant sensors. These have enhanced scientific understanding as well as influenced our daily lives. IVF will undoubtedly do the same for reproductive endocrinology. It is not beyond the scope of one's imagination that in future of our field, guard against an uncontrolled technology, and recognize that, paradoxically, constraint may ultimately provide greater freedom. The integration of craft and commerce as well as maintaining traditional ideals must be constructively planned for now.

EPILOGUE

Perhaps some decades from now a child ironically conceived in fallopio will go into the field of reproductive endocrinology as a technodoc. She will look back at us and snicker at our naivete. She will understand well this in vitro process that we are now so crudely manipulating. She might think: How quaint that a 20% success rate was considered acceptable; that we were unaware of the repressor substances in follicular fluid which inhibited proper maturation which, once discovered, allowed for an 80% success rate. Even then, when newborns may be delivered to their waiting parents on Petri platters, when a masked gynecologist holding a laparoscope may have replaced the Virgin Mary, kneeling,[13] I would still rather have been Wolfgang Amadeus Mozart than Arthur Rubinstein.

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the near future ovum will be harvested from ovaries profused extracorporeally and reproduction will no longer be a sexual function.

Just as the economy moves in cycles responding to Kondratieff waves, so science moves in cycles. A scientific discipline will have a major imaginative breakthrough, followed by rapid innovative growth. This leads to the inculcation of this new information, and then eventual integration, and slow growth. This cycle is seen in anthropology and entomology as well as in reproductive endocrinology. Therefore, an individual who is interested in fertility, who is not involved in IVF, is very similar to the West Point graduate who is educated in military science but never goes to war. For that reproductive endocrinologist who does not grow with the in vitro field will rapidly become arcane. This, then, is the challenge technology has given to our generation. Yes, we are all extremely fortunate to be around at this important time. But we must take charge of the

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THE FEDERAL EMPLOYEES FAMILY BUILDING ACT
FACT SHEET

What does the legislation do?

* The bill requires that all Federal employee health insurance plans cover family building activities.

* Family building activities include:
  a) medical procedures necessary to overcome infertility so as to achieve pregnancy and to carry it to term; and,
  b) necessary expenses related to the adoption of a child.

* Covered adoption expenses include agency and placement fees, legal fees, counseling fees, medical costs, foster care charges, and travel costs.

* The employee may use sick leave for family building activities.

* The employee may appeal any interference with his or her right to leave for family building activities.

Why is the legislation needed?

* Infertility is a major health problem.

One out of six couples have a problem conceiving.

* Fairness and equity require insurance coverage.

Federal employees have the costs of pregnancy and childbirth covered by health insurance, but the costs of infertility treatments and adoption currently are not.

* The costs of infertility treatment and adoption can be prohibitively high.

The risk of infertility is 1 and 1/2 times greater for blacks than for whites, and is more common among couples with less than a high school education. Yet, whites and those with higher incomes are more likely to pursue infertility treatment and adoption. Just as middle income employees need insurance to help with the costs of heart problems or broken bones, they should receive similar assistance to build families.

What will be the results?

* Adoption and infertility treatments will become less a privilege of the affluent, and more available to employees of different economic classes.

* Treatment of infertility will help provide answers to the causes and prevention of such problems.

INFERTILITY FACT SHEET

What is it?

* Infertility is the failure to conceive after one year of trying without contraception.

* Many disease conditions and environmental factors can affect the reproductive process and interfere with normal reproduction.

* Pregnancy reduces the risk of ovarian, endometrial, colon, rectal, breast and large bowel cancers. Successful treatment of infertility might ultimately result in significant reductions in the occurrence of these illnesses and related treatment costs.

* Stresses of trying and failing to conceive for an extended period have serious effects on individuals, relationships, careers, and health.

Who is affected?

* Of the 55 million American women of child bearing age (15-44), 10% have trouble conceiving.

* In the last 20 years, the number of infertility-related visits to doctors has nearly quadrupled.

* Nearly 1 million couples seek medical advice or treatment for infertility each year.

* Infertility among couples aged 20 to 24 increased an alarming 177% between 1965 and 1982.

* In 40% of infertile couples the female is infertile, in 40% the male, and in 20% both have fertility problems.

* Infertile couples are more likely to be black, more likely to be older, and more likely to have received less than a high school education. Yet, a larger proportion of younger and white couples pursue treatment.

What are the costs?

* The average fee for infertility care (consultation, diagnosis, and surgical treatment) is between $2,500 and $3,000.

* In 1982, reproduction-related health care accounted for only 5.5% of total health care spending. Only 1% or less of that 5.5% figure was for treatment of infertility.

- total health care spending	$322 billion
- reproductive-related	$17.8 billion
- infertility	$200 million

* It has been estimated that $200 million was spent in 1982 for infertility treatment - if the 1987 amount is twice as high, the overall estimate for reproduction-related health expenditures would increase by only 1%.

* The costs of not treating infertility are substantial:
  - loss of human resources, loss of workforce.
  - increased risk of cancer, and consequent high medical costs. in women without children.

What can be done?

* 50-60% of infertility can be successfully treated with drugs or surgery and result in live births. Other means of treating infertility include:

* artificial insemination:

- An estimated 10,000 couples per year turn to artificial insemination. About 80% of women receiving artificial insemination conceive within 3-6 months. In 1984, an estimated 8,000 children were born as a result of artificial insemination.

- Usually 2 or 3 inseminations are performed each cycle at a cost of approximately $75 per insemination.

* In vitro fertilization (IVF):

- A process by which an egg is fertilized outside the body of the mother and then transferred back into the mother to establish a pregnancy.

- IVF has matured from an experimental therapeutic procedure to an effective and widely applied infertility treatment. There are now 220 IVF programs worldwide with about 75 active IVF programs in the United States. An estimated 12,000-15,000 IVF procedures have been performed worldwide, resulting in over 2,000 live births.

- Among experienced IVF programs, pregnancy rates have risen steadily over the past 5 years into the range of 20 to 30%. The IVF success rate of 20% per attempt is comparable to the rate for fertile couples trying to conceive.

- IVF procedures generally cost $3,000 - $5,000 per attempt; often several attempts are required to achieve a pregnancy.

- IVF aids in the study of contraceptives, the causes of infertility, cancer, the effect of drugs on the embryo, chromosomal abnormalities, and cell growth and differentiation.

ADOPTION FACT SHEET

* Adoption is a legal procedure in which a person or couple takes a child that is not their offspring into the family and raises it as their own; the child may be unrelated to either adoptive parent, may be a child of one member of the couple, or may be related in some other way to the adoptive parents.

* In 1982, there were 141,861 adoptions. Thirty-six percent of these were unrelated adoptions:

  - 17,602 healthy infants
  - 5,707 foreign adoptions
  - 14,005 special needs
  - 9,591 adoption of children by foster parents

* In the U.S., it is estimated that there are at least 2 million couples of childbearing age, plus an estimated million single persons, seeking to adopt,.

* In 1982, 38% of unrelated adoptions were arranged by public agencies; 33% by private individuals; and, 29% by private agencies.

* Women who adopt tend to be white and of higher educational and income levels. Black children constitute 14% of the child population, 34% of foster care, and 41% of children free for adoption.

* The cost of adoption can range up to $10,000, with the average non-profit agency fee in 1985 being $6,000.

* The Federal government has taken a very high profile in urging private companies to provide adoption benefits for their employees but offers none to its own.

* Almost 50 private employers offer an adoption benefits plan that financially assists employees with expenses related to the adoption of a child or provides leave for the adoptive parent.

* There are more than 36,000 special needs children now waiting to be adopted.

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